



Qualitative Study among Most-at-Risk Populations for HIV and TB in Tashkent City

PROGRAM TITLE:	USAID Dialogue on HIV and TB Project
COOPERATIVE AGREEMENT NUMBER:	176-A-00-09-00023-00
PROGRAM SITE COVERED BY REPORT:	Tashkent City, Uzbekistan
QUALITATIVE RESEARCH PERIOD:	May 2011
SUBMITTED TO:	Elmira Imambakieva and Shana Aufenkamp
SUBMITTED BY:	Irina Yuzkayeva
PREPARED BY:	Arustan Joldasov and Mavluda Eshtukhtarova
DATE:	June 2011

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GLOSSARY AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ARVT	Antiretroviral therapy
CDC	Centers for Disease Control and Prevention
CIS	Commonwealth of Independent States
DOTS	Directly Observed Treatment, Short-course
F	Female
FGD	Focus group discussion
HIV	Human Immunodeficiency Virus
IDI	In-depth interview
IV	Intravenous
KVD	<i>Kozhno-venerologicheskii dispanser</i> (Dermatology and Venereology Center)
M	Male
Mahalla	A neighborhood run by a formal committee
Mama Rosa	Female pimp
MARP	Most-at-risk population
MoH	Ministry of Health
NGO	Non-Governmental Organization
PLHIV	People Living With HIV
PLHIV-TB	People living with HIV and TB
Project HOPE	Project HOPE – The People-to-People Health Foundation
PWID	People Who Inject Drugs
STI	Sexually transmitted infection
SW	Sex Worker
TB	Tuberculosis
TBP	TB patient
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

SUMMARY

The present report relates the findings of a qualitative study conducted in May 2011 by the Expert-Fikri Center for Social Research in Uzbekistan on the knowledge, attitudes, and behavioral practices related to receiving services from health care facilities and other institutions (mahallas, the non-governmental non-profit organization Contact, etc.) among people at risk of contracting tuberculosis (TB) and HIV or those who have already been diagnosed with these diseases.

Project HOPE, or otherwise known as The People-to-People Health Foundation, Inc., acts under the USAID Dialogue on HIV and TB Project., and instructed the Expert-Fikri Center for Social Research to implement this study of TB and HIV health services.

The USAID Dialogue on HIV and TB Project aims to reduce the risks associated with contracting TB and HIV among most-at-risk populations (MARPs) by providing the most recent and adequate information, as well as by increasing access to and improving the quality of services.

The opinions of informants and of those already diagnosed with TB and HIV on their knowledge needs, attitudes, services, including information services are summarized in the following report.

ACKNOWLEDGEMENTS

The authors of this report would like to thank the outreach workers – Yelena Smirnova, Maxim Suleimanov, Alexander Trotsenko, Jakhangir Umarov, and Svetlana Yeremenko – for their valuable assistance in recruiting respondents, as well as the respondents themselves, who felt the importance of participating in this study and were honest in expressing their opinions. We cannot mention their names, as we are obliged to keep their participation in this study confidential.

GOAL, QUESTIONS AND EXPECTED RESULTS

The goal of the study was to obtain information on the respondents' knowledge, attitudes and behavioral practices related to TB and HIV, and to present the findings in an analytical report.

The study served to explore the following questions:

- What are the knowledge, attitudes and behavioral practices among populations at risk of contracting TB?
- What are the knowledge, attitudes and behavioral practices among populations at risk of contracting HIV?
- What are the opportunities for and obstacles to receiving needed services and assistance, including treatment for TB and HIV, among most-at-risk populations (MARPs)?

The expectation is for the results from this study to be used to develop evidence-based strategies for 1) teaching MARPs healthy HIV and TB treatment seeking behavior and 2) improving access to medical services for diagnosis and treatment of HIV and TB.

CONCLUSIONS AND RECOMMENDATIONS

This report is based on the respondents' perceptions, opinions and experience, and may not quite accurately reflect the reality of the situation. These perceptions are, nevertheless, part of the reality and the USAID Dialogue on HIV and TB Project should work towards improving the situation, which may include working to correct inaccurate perceptions.

Given that the study did not employ quantitative, statistical analysis, each of the respondents' words were equally valued as reflecting the reality and were considered during the analysis of the MARPs' knowledge, attitudes and practices.

The present study's data has allowed us to state or assume the following:

Activities implemented in Uzbekistan by local and international organizations under previous programs, as well as projects aimed at reducing the risks of and demand for injecting drug use and commercial sex, have had a significant impact. The effects of these activities and projects are still visible even after a drop (reported by the respondents) in the previously large number of prevention programs in the country (in which non-governmental non-profit organizations and outreach workers were involved). These prevention programs were focused on reducing the risks of MARPs and providing them with psychological, medical and social assistance.

The respondents noted a significant drop in the number of people who inject drugs (PWID) and in the supply of injecting drugs in the illicit drugs market as a result of the impact of various projects. Also noted by the respondents was a decrease in the number of teenage sex workers

(SWs) and demand for their services. The respondents did, however, report an increase in the number of SWs aged over 18 and of MARPs living with HIV and sick with TB.

In the past, you go the entrance [of your apartment building] and there wouldn't be so many cigarette ends lying around, but there would be syringes. It was that kind of time.
4-M-PLHIV+TB

Knowledge

Information on risks is delivered to MARPs by various government and non-governmental organizations, and is spread by MARPs themselves as well. Each respondent already knew some detail about certain symptoms or about the diseases they are sick with. The respondents were most knowledgeable about transmission routes and prevention methods, but less aware of where to go for voluntary counseling and testing (VCT). They were even less aware of the experiences of other MARPs seeking VCT services, which could serve to provide positive attitudes towards seeking VCT services. It should be noted that all the respondents had been infected with and treated for an STI or had received treatment for addiction to injecting drugs. Despite having gone through such experiences, the respondents' knowledge was fragmentary, incomplete and not systematic.

MARPs receive information through various channels: at polyclinics, maternity houses, hospitals, trust points, AIDS centers, on TV, over the radio, through printed material, outside, on public transportation, and etc. This information, however, is not sufficient nor accessible for MARPs, and aimed at being more intimidating rather than informative.

The lack in MARPs' knowledge and in using the albeit insufficient knowledge in practice is a result of a significant reduction in recent years in the number of channels for reaching MARPs and the content of information that is delivered to MARPs. The information that reaches MARPs is superficial and only hinted at – making MARPs guess at what the information is trying to say about STIs or HIV than actually understand what is being conveyed.

Information is at times presented in languages or alphabets that make it difficult for MARPs to comprehend the information. Russian speakers do not understand information in Uzbek, and vice versa. Adults who were taught the Cyrillic alphabet do not understand information written using the Latin alphabet, and young people who have been taught the Latin alphabet do not understand information written using the Cyrillic alphabet.

MARPs need to be provided with key information that is tailored to them about who is eligible to seek support and services, as well as where, how and whom they can turn to with his/her questions, risks and problems. In such messages, the main words should be “voluntary,” “free,” and “anonymous.” After delivering such messages, what remains to be done is to create the conditions for and ensure that receiving information and required services be free and anonymous, and that those who provide information and services be friendly. The respondents particularly noted the unfriendliness at the KVD (dermatology and venereology center).

Attitudes

Attitudes are being formed under the influence of the following factors:

1. The MARPs – particularly the TB patients (TBPs) and people living with HIV (PLHIV) – note the friendliness of doctors and nurses, the timeliness of their services, as well as the attention and control they provide for adhering to the course of treatment, the procedures, and taking medicines. If we compare these results with the data from a study conducted 10 years ago, we can clearly observe positive changes in the attitude of health providers towards PLHIV – from discrimination to tolerance and friendliness – particularly at AIDS Centers, TB dispensaries, and health facilities in penitentiary institutions.
2. The respondents mentioned cases of poor hygienic and sanitary conditions, disregard of precautionary measures against infection, and the low quality and unreliability of testing, diagnosis and prescribing courses of treatment. The TBPs believe that this is related to the lack or low quality of the equipment, X-ray film and chemicals. They mentioned cases when, for example, TB was detected not after a sputum analysis and X-ray exams, but only after a lengthy process of examinations and treatment of other diseases or after tomograms. These negative circumstances influence the formation of negative attitudes towards seeking VCT and treatment: distrust towards TB diagnosis becomes the basis for distrust towards VCT as a whole.

Experiences

Results from all the topics explored in this study show that MARPs are not being subject to stigma and discrimination from health providers, with the exception of *KVDs*. Stigma and discrimination is also present where they reside – from neighbors, district police officers and staff of self-governing bodies. The degree of stigma and discrimination that is present, however, has significantly decreased if compared to 10 years ago and continues to decrease. The PLHIV and TBPs note this decrease among those who they most frequently interact with – neighbors, colleagues, relatives and family members.

A number of factors are reported to have contributed to the significant decrease in the number of cases of suicide among PLHIV and TBPs, which can occur either after they learn about their HIV status or TB diagnosis or which can occur during the course of treatment. These contributing factors provided by staff of services (polyclinics, AIDS Centers, trust points, and hospitals) include friendly attitudes, medical skills, especially skills in providing psychological support, and adhering to the principles of voluntariness for treatment of STIs, TB and HIV. The respondents mentioned cases when they have received services not only upon when going to the health facilities, but also when staff from these facilities reminded them to do so, either with a phone call or a personal visit. Respondents were reminded about their treatment course, about the next stage of examinations, or about necessary tests when staff members came to their homes to take blood for analyses. Respondents were also given reminders about their treatment when staff members delivered medicine to their homes, which occurred when respondents could not go to the health facility themselves.

Barriers to receiving counseling and testing were reported among the so-called “newcomers”. These are people who have come to Tashkent from the villages to earn money (including SWs)

or for personal reasons. They either do not have residential registration in Tashkent and, thus, cannot receive services from health facilities, or do not know about their right to anonymously seek the services of AIDS Centers or trust points. According to the respondents, some of these newcomers are using the services of “inexpensive” SWs without using condoms and do not get tested for STIs or HIV afterwards.

Needs

MARPs are in need of a wide network of trust points (AIDS Center branches) outside of public health facilities. They suggest that some sorts of clubs/communities/associations be created at these trust points for MARPs to interact with each other and share their experiences of receiving information and services. This network would also allow MARPs to provide moral support for each other, as well as support related to protecting their rights and interests when they are violated.

Currently, the respondents’ knowledge, attitudes and practices are not consistent and uncoordinated – like their efforts. This will not allow for a synergetic effect to ensure the sustainability of programs. Nevertheless, some PLHIV participate in virtual communities on free social networks on the Internet, where they already exchange knowledge and experiences. Such virtual networks could serve as a platform for programs to reach MARPs with information on services that are in-demand or services that are important and necessary, but that they may not necessarily be aware of. This would include VCT and services that work to build up MARPs’ knowledge level. Such a community could be piloted by Project HOPE and then expanded, if successful, to other sites and blogs that also serve other CIS countries. This could potentially be used as an instrument for monitoring the social and medical needs of PLHIV and TBPs, including their knowledge needs.

Websites and blogs on the Internet could become an effective tool for monitoring the quality of services provided and for adapting services to women who hold “ethnic complexes,” are dependent on men’s risky behaviors and who require anonymity. Without addressing the aforementioned points, women tend to seek assistance and information too late.

The respondents suggest that effective printed informational materials be supplemented by DVDs that can be watched individually or in groups that include words from specialists or include information on where to go with questions.

Knowledge, attitudes, experiences and needs of TBPs and PLHIV

The TBPs and PLHIV have complete and comprehensive knowledge about their diseases, prevention methods, and treatment procedures, as well as knowledge about how to protect people around them from getting infected. Some of them use their knowledge in practice. The TBPs and PLHIV, however, acquired this knowledge after they had already found out about their HIV status, after they were diagnosed with TB, and after having received some services and treatment. Before all this, their knowledge level was the same as of those who do not have HIV or TB.

It should be noted that, according to the respondents, there are those who hide their medical status in an attempt to avoid losing their jobs or be subject to stigma. These people either have separate or co-infections of TB and HIV, and are secretly diagnosed through doctors they know. These sick people also avoid being registered and being under the control of the AIDS Center, TB dispensary, medical-epidemiological services, and district doctors. Some of these people are working in the service sector (as cooks, waitresses, dishwashers, sales people, etc.) and others hold “high-ranking” positions (the respondents referred to government employees or heads of businesses as “high-ranking” positions).

Both information and treatment are, overall, accessible to TBPs and PLHIV. When they seek services, receive exams, or are hospitalized, these people are offered free access to treatment. The only problems that TBPs and PLHIV experience when they receive inpatient or outpatient treatment are a lack or absence of control for taking medicine (particularly during DOTS), scanty meals and poor nutrition, and cases of experiencing poor conditions (for example, leaking from the ceiling of a facility after rain). The TBPs and PLHIV, additionally, do not have enough money to cover the costs for proper nutrition, services from nurses, syringes, IV sets, and medicine – only a part of which is included in the prescribed fixed course of treatment under DOTS or antiretroviral therapy (ARVT). There are also additional costs for concomitant diseases and conditions. TBPs say that, on average, 1 million som is needed to treat TB.

Particularly needed for TBPs and PLHIV during and after hospitalization are psychoanalytical/psychological assistance and, especially, social support and assistance. Necessary social support includes an income-making job (at the minimum, domestic work), monetary and food aid, as well as the assistance of social workers during periods of inpatient treatment or during an outbreak of the disease (when the patient is away from his/her children or family members). Monetary assistance to cover necessary transportation costs to health facilities and for purchasing medicine is also needed. Most of the TBPs and PLHIV come from low-income families, have lost their job, or were already unemployed when diagnosed with the disease. This inadequate financial situation brings about depression and results in malnutrition, while the lack of money for medicine makes them interrupt or discontinue treatment and post-treatment prophylaxis. As a result, the TBPs and PLHIV begin self-treatment. All of these factors worsen the sick individual’s condition and may result in their death or repeat visits to state health institutions.

When repeat visits are necessary after treatment is interrupted due to the abovementioned reasons, the health institutions (TB dispensaries, AIDS Centers, polyclinics, the Virology Institute, etc.) incur even larger expenses that could have otherwise been saved and used for more efficient forms of assistance, towards services for TBPs and PLHIV, and for the creation of incentives for the personnel of these institutions. TBPs and PLHIV that have received services from these health facilities stated that the budget of these facilities and the salary level for the personnel do not match up to the complexity of the work, the work load, and the qualifications of the specialists at all levels. They also stated that the budget is not able to cover the expenses of repeat patients.

BACKGROUND

Since 1997, USAID has focused significant resources on addressing the HIV and TB epidemics in the Central Asian Republics: Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, and Uzbekistan. These countries have adopted and are implementing government programs on the control of HIV/AIDS and TB. These programs are supported by international donors, such as USAID, the Centers for Disease Control and Prevention (CDC), World Health Organization (WHO), and the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria.

In order to address the problem of HIV and TB, these national programs work among both the general population and most-at-risk populations (MARPs), including:

- People who inject drugs (PWID);
- Sex workers (SWs);
- Labor migrants;
- People living with HIV (PLHIV); and
- TB patients (TBPs).

The USAID Dialogue on HIV and TB Project targets the abovementioned populations, who are most at risk of contracting HIV and TB.

This study was conducted for the following purposes:

- To obtain information among MARPs on their knowledge, attitudes and behavioral practices related to TB and HIV; and
- To identify opportunities for and obstacles to MARPs seeking medical assistance and receiving treatment.

The results of the study will be used to review the National Communication Strategy, the development of informational programs and informational-educational materials on TB and HIV for MARPs.

METHODOLOGY

Study methods

This study utilized qualitative methods for data collection and analysis in order to learn about MARPs' practices regarding seeking medical assistance and receiving treatment. Specifically, focus group discussions (FGDs) were conducted with PWID, SWs, PLHIV and TBPs, and in-depth interviews (IDIs) were conducted with PLHIV diagnosed with TB.

Sample site

Tashkent City

Control and supervision

Overall control and supervision of the study was provided by representatives of Project HOPE and other organizations.

Study preparation

The USAID Dialogue on HIV and TB Project organized training sessions for representatives of the Expert-Fikri Center for Social and Marketing Research to train its staff on skills for communicating with MARPs.

Sample size

In total, 12 FGDs were conducted:

- 2 FGDs each with each group – PWID, SWs and PLHIV – on TB;
- 2 FGDs each with each group – PWID, SWs and PLHIV – on HIV.

Additionally, 10 IDIs were conducted with PLHIV diagnosed with TB.

Questionnaires and discussion guides

The questionnaires and discussion guides for this study were prepared in Russian and Uzbek. The questionnaires and discussion guides included questions and instructions for probing certain topics and responses.

Moderators

The FGDs and IDIs were moderated by interviewers from the Expert-Fikri Center who had prior experience working with vulnerable populations.

Focus group discussions

For each FGD, the first respondents were recruited via outreach workers from the USAID Dialogue on HIV and TB Project who work with MARPs. The subsequent respondents were recruited by the respondents themselves. The criterion for selection was that the respondent had not interacted with an outreach worker from any project or program.

The size of each group ranged from 9 to 12 people, with an average of 10 people in each group.

The FGDs lasted approximately 1 to 2 hours.

Each FGD was conducted by an experienced moderator, who was assisted by 2 people: one person who took notes, and another person who controlled the recording equipment. Each recording was transcribed word-for-word and combined with notes on the respondents' nonverbal communication.

In-Depth interviews

PLHIV with TB were recruited via AIDS centers and TB dispensaries using the same sampling procedure as for the FGD respondents. In total, ten one-hour IDIs were conducted with PLHIV diagnosed with TB. All PLHIV were ill with TB during the time of the interview.

Data collection facility

FGDs were conducted at the Expert-Fikri Center's facility in a comfortable, sunny and properly ventilated room, where the respondents were guaranteed confidentiality. A comfortable temperature was maintained in the room, and the respondents were offered tea, coffee, water and sweets. Two bathrooms were located near the room, and the respondents were informed about the bathroom locations before the FGDs began.

The room was equipped with necessary study equipment, including a one-sided mirror. The respondents were seated around an ellipse-shaped table that allowed for all respondents to see and hear the moderator and each other.

IDIs were conducted either in locations convenient for the respondents or at the Expert-Fikri Center in the same room described above.

Data analysis

All FGDs and IDIs have been presented in the form of transcripts and are also present in this current analytical report. All conclusions in this report are based on the respondents' words. This report is meant to capture the diversity of knowledge, attitudes and practices rather than provide a quantitative representation of the MARPs' situation. Quotations from the transcripts are included throughout the report in order to complement the conclusions made. All quotations are labeled with the respondent's MARP group, gender and age.

Ethics

Study participants were informed that FGDs and IDIs were being aurally recorded and that people were in the next room with a one-sided mirror that allows them to see the study room. All respondents were guaranteed confidentiality during the full study process from data collection and analysis to storage following analysis.

Each respondent was informed in written form about his/her right to refuse their participation in the study as well as their right to discontinue participation at any moment during the FGD or IDI. Each respondent signed a consent form that stated that he/she agrees to voluntarily participate in the study and that he/she will not disclose the content of the discussion or interview.

STUDY RESULTS BY MARP GROUP

This report is based on the respondents' perceptions, which may not quite accurately reflect the reality of the situation. There is a need to improve both the real situation regarding services for MARPs and to correct any inaccurate perceptions that MARPs may hold.

Results on knowledge, attitudes and practices are presented in the report in separate sections, which together create one, albeit mosaic-like, picture.

As the study methodology did not call for a statistical analysis of the data, each respondent's words held an equal chance for being considered and included in this analytical report.

KNOWLEDGE, ATTITUDES AND BEHAVIORAL PRACTICES REGARDING TB AMONG SWs

Knowledge and sources of information related to TB

The SWs stated that opportunities are available for acquiring knowledge on TB should he/she wish to do so. SWs could learn information from, for example, a doctor or nurse at a polyclinic or on the Internet. In order for them to make this effort to find out information, however, there must be an impetus. This impetus may include being sick with TB themselves, or a family member or relative being diagnosed with TB.

The SWs reported receiving **information related to TB** through the following sources: fictional and historical literature, Russian TV programs such as "Health," current or former TBPs, and printed materials (posters and brochures at polyclinics). The SWs believe that there are not enough printed materials available and that those that are available are not appealing. Fictional and historical literature as a source of information tends to form an overly romantic image of TBPs and the disease itself. As such, the danger of this kind of literature is that it could potentially minimize TB-related fears.

SWs' attitude towards TB was mixed: extending from fear of death to laughter at the mention of TB symptoms and their proximity to the disease.

SWs' knowledge of TB symptoms was in bits and pieces and not comprehensive. It is clear that information on symptoms should be presented in a clear, comprehensive table and should emphasize the risk of bronchitis and pneumonia turning into TB.

SWs mentioned the following particular **conditions for getting infected with TB**: in prisons, through labor migration to Russia and Kazakhstan, and through poor nutrition in low-income families.

The SWs, as a whole, are aware of **methods of protection against TB**, but, again, this knowledge is fragmentary and not comprehensive. It is notable that the SWs point out dog meat as one of the prevention and treatment methods. The SWs mentioned that some TBPs are aware

of the transmission routes and take preventative measures, while others hide their disease, and in doing so infect their family members and relatives.

The general conclusion among SWs is that there are no prevention methods that guarantee protection from TB infection, but that the methods lower the likelihood of getting infected. It is notable that there is a belief among SWs that psychological resistance can lower the likelihood of getting infected with TB.

Illustrating the SWs' knowledge needs is the following quote from a FGD: "We want to know everything – from the causes and signs of TB to the treatment procedure and its effectiveness."

Preferred forms of receiving information include printed information such booklets or posters at polyclinics, as well as short videos on TB (like the ones on HIV). SWs would also prefer to receive verbal information through discussions with physicians and obstetrician-gynecologists' within the privacy of their offices, or in areas where safety engineers work (areas that are connected to dampness, colds, and breathing polluted air and dust). Other prime locations include places where SWs gather and look for work and classes at school, since learning at a young age is more interesting and information is more easily remembered.

The SWs also noted that they have seen related TV programs on Russian TV channels but not on local TV channels.

Seeking information and assistance

SWs think that **seeking assistance** happens in the following order: first from family and close relatives (informing them, so that they can protect themselves and not get infected; asking them for help), then to the polyclinics, and then further according to the directions and prescriptions of doctors, including doctors at TB dispensaries and polyclinics.

Those ill with TB – particularly those with small children – do not go to TB dispensaries, as they cannot leave their children alone. One SW recommended that social workers provide such assistance and look after children of those going to seek assistance.

SWs consider it pointless to go to mahalla committees for social assistance.

Some SWs believe that **seeking treatment** is useful, and that treatment should be sought in a timely manner during each season of the year, since TB is curable. This is especially true of TB that is detected early and when patients adhere to treatment. Other SWs believe that TB is a fatal and incurable disease, and that seeking medical assistance will only prolong your life some years. It is clear that messages for SWs should strive to minimize this fear.

SWs believe that individuals should receive treatment from "their own" doctors, whom are trusted to keep information confidential. They believe that individuals should not go to polyclinics for treatment and instead distrust them, since the SWs fear that these impersonal institutions will inform the police about an individual's disease if an STI is detected during the TB diagnosis process. Thus, the SWs instead turn to private clinics and doctors, who provide

examinations and treatment unofficially, or resort to self-treatment. “Mama Rosas” (female pimps) provide assistance to SWs during this process of seeking assistance or self-treatment. These Mama Rosas may potentially be used as a channel for distributing printed materials on TB to SWs.

Opportunities for and barriers to receiving consultations and treatment for TB

Opportunities for receiving diagnostic services, consultations, support and treatment for TB are sufficiently high. Similar services are provided at a number of health institutions, from polyclinics to dispensaries.

Nevertheless, there are barriers to receiving these services. The respondents reported the following obstacles and fears:

- The large amount of time and effort needed for the X-rays and doctor examinations;
- The need to interrupt income-making or other regular activities or studies for a long period of time;
- Feeling already doomed to die and thus experiencing disinclinations to be pulled into the throes of treatment and treatment costs;
- Lack of knowledge about and approval of DOTS;
- Distrust of free treatment services in general, or distrust of the quality of free treatment services for specifically TB and other associated diseases;
- Losing confidentiality upon seeking assistance; and
- Stigma.

Some incorrect informational materials contribute to the stigma. The SWs mentioned the repugnant content of posters on TB that creates a negative image of people ill with TB.

Stigma is rarely manifested by family members. The manifestation of stigma is high, however, among neighbors and acquaintances. These individuals find out about people being ill with TB from the TBPs themselves, from district police officers or from representatives of the mahalla committee.

The SWs’ response to external stigma is self-stigmatization.

It’s a shameful disease, because it’s contagious. SW-F-35

SWs have come to the conclusion that people are too dependent on the ill individuals, who cannot care for others, and that treatment should be compulsory right after the detection of TB.

SWs consider psychological and social support to be important for people ill with TB.

KNOWLEDGE, ATTITUDES AND BEHAVIORAL PRACTICES REGARDING HIV/AIDS AMONG SWs

Knowledge of HIV/AIDS

The respondents are sure that HIV and AIDS are one and the same incurable disease that results in a fatal outcome. They, however, are not aware of the mechanism of infection and of what takes place in an infected person's body. Some SWs can state what AIDS stands for in a clear manner: "acquired immunodeficiency syndrome." One SW was sure that HIV is a disease that quickly leads to death, while others believed that you can live a long life with HIV and AIDS if you lead a healthy life style and receive treatment.

Something changes in the blood, and people ill [with the disease] don't live long. SW-F-30

HIV definition and symptoms

The respondents either do not know how to tell an HIV-positive person from someone who is HIV-negative, or believe that it is not possible to tell the difference. They think you can only find out if you have HIV through a blood test or if you have wounds on your body that do not heal. Others disagree with the latter, saying, that a diabetic person could also have such wounds on his/her body. Some SWs mentioned the following signs: that PLHIV are always hiding from the sun, they have a constant body temperature of 37.5 degrees, they lose weight, have yellowness in their eyes, and their skin color changes. It is possible that they confused the signs of HIV with the signs of concomitant diseases, such as TB or hepatitis.

I have an acquaintance, who is sick with HIV. I continue to meet with her. By her appearance, I would not have thought that she has HIV. I noticed that if she gets cut, the wounds do not heal. SW-F-35-married

Sores that do not heal appear on the body. SW-F-40

I knew a boy who died [of AIDS; he injected drugs]. He said that they can't stay in the sun. SW-F-37-married

Some SWs do not know that HIV can provoke or aggravate other diseases. Others link HIV to TB. They knew of this connection between HIV and TB from experience rather than from other information sources.

My brother is sick with tuberculosis. We visit him in the hospital where a lot of young people die. He told me that a lot of them are sick not only with tuberculosis but also with HIV. SW-F-30

Knowledge of HIV transmission routes and protection methods

The SWs are aware that HIV can be transmitted through sexual contact, through PWID sharing needles/syringes, and through contact with the blood of an HIV-positive person or objects that have this blood on them. They also know that HIV can be transmitted from mother to fetus or to her breastfed child. These transmission methods were mentioned in a fragmented fashion by different SWs.

The infection is only transmitted through blood. It's not transmitted by shaking hands with someone. SW-F-34-married

And through breast milk and when the baby is still in the mother's womb. SW-F-30

According to SWs, the primary prevention method from HIV during sexual contact is the use of a condom. In other situations, an individual should not use another person's syringes or other instruments that may carry the blood of an HIV-positive person.

You can get infected during a dentist appointment. SW-F-31-married

I'm afraid of going to the polyclinic to visit the gynecologist. SW-F-30

Because nothing is sterilized there. SW-F-31-married

Sources of information on HIV/AIDS

SWs receive information on HIV/AIDS from the following sources (placed in order, starting from the most common sources of receiving information – whether correct or potentially incorrect):

We see everything ourselves. We warn each other. SW-F-34-married

For example, neighbors gather at night and discuss these things. SW-F-30

When you go on the bus, people discuss this. It became scary to go to the polyclinic, the hospital, to a dentist. People say that there's a high likelihood of getting infected through a syringe in these places. SW-F-31-married

About half a year ago, I found out from my neighbors that there is even an AIDS Center. SW-F-35-married

We heard information about AIDS at school. SW-F-21-married

It was in the newspaper Darakchi, Khumo. SW-F-31-married

There are posters and brochures at the polyclinics. All SWs

My friend told me about it. We were cooking together. She told me to be careful if she gets cut, because she has HIV. SW-F-35-married

I saw a film of sorts on TV [on the channel Yoshlar]. There was a guy and a woman. The woman was sick with HIV and she told him about this. They got married. The guy got infected as well. They had a healthy daughter. SW-F-37-married

Some time ago, they showed on TV how a girl went to work in the Emirates and happened to go to a Mama Rosa [female pimp]. A client purchased her [from the Mama Rosa]. He got her on drugs. She returned infected with HIV. SW-F-31

Several years ago, there used to be events on HIV/AIDS in the parks Baburkanal and Ulugbek and on Broadway. People, whose friends had died of HIV/AIDS put up posters there. There's nothing like this nowadays. SW-F-37-married

I saw it on a site on the Internet and heard about it on the radio on HIV/AIDS Day. They provided statistics. People made anonymous calls. SW-F-40

Availability and barriers to receiving information on HIV/AIDS

While basic information on HIV is largely available, this is not the case with more detailed information that SWs need. The SWs, additionally, mentioned issues with the form and content of some presented information, where they noted that the information contains text and uses terminology that is not understandable. They also noted that information is rarely communicated, and that information topics are not interesting or attractive.

Most of the posters are in Latin [written using the Latin alphabet]. They don't show anything about this on TV. SW-F-35-married

There's not enough information on TB or the information is not understandable. If they put in video spots in between sections of films, then whether you want to or not, you would see them. SW-F-26

They sometimes show something round and HIV in Uzbek – “OITS” – or a girl sitting and crying. What is this picture about? It's not understandable. SW-F-30

They should show something like in the cigarette ad. A guy is walking and smoking and burning away with his cigarette. This is something that you'll remember. SW-F-26

There's little in the newspapers. On the radio – only on Russian radio. SW-F-31-married

There are posters in the hospitals, but doctors don't say anything about it. They say, “Go there and read it yourself.” SW-F-24-married

Based on the aforementioned barriers to obtaining knowledge, the SWs offered their own suggestions about information content, and the desirable forms of information, including information on how to deal with doctors who have suspicious medical instruments.

What are the routes of HIV transmission, especially, if you don't know whether a person has HIV or not? We can bring our own syringes, but we can't bring our own instruments to the doctor's office! SW-F-34-married

For example, how can you be sure that the instruments in the hospital are safe? SW-F-31-married

It would be good to receive information in the form of this sort of discussion/conversation [FGD] or on video discs with interesting pictures. SW-F-31-married

They should hold discussions/conversations with real people who are sick. Anywhere nearby in your mahalla. Trust points are a bit far away. SW-F-30

They should distribute brochures where it says the telephone numbers of trust points and where you can go to ask questions and have your blood tested. SW-F-31-married

It's better to hear real life stories and examples than lectures. Meetings with PLHIV. SW-F-40

TV spots should last no more than 5 minutes and meetings should go up to 45 minutes long. SW-F-26 and SW-F-37-married

Although some SWs consider the mahalla to be a source of stigma and losing confidentiality, they think that the mahalla could serve as a channel for spreading information in the mahalla. They recommend that only printed material be disseminated and that mahalla residents not be picked out and mentioned to provide examples about the infection.

HIV risk groups

The SWs, as a whole, are aware of the groups at risk of contracting HIV. It is important to note that the perceived risk is less related to getting infected by injecting drugs or through sexual contact (primary infection), but more about getting infected in a secondary manner, such as from someone who is already infected with HIV. The SWs, in this way, link getting infected with HIV more to the likelihood of having a HIV-positive client, as opposed to linking this possibility of HIV infection to the inherent risk of having unprotected sexual contact with various clients. It is clear that this perception needs to be changed in order for SWs to take measures to protect themselves, measures that are independent of their likelihood of encountering a client who is HIV-positive.

The groups at risk are prostitutes and drug addicts. SW-F-21-married

They are promiscuous and have sexual relations with a large number of clients. SW-F-31-married

It's unlikely that they all use condoms. SW-F-30

The Mama Rosas told us, I think, in 2008 and showed us a composite picture: A man who got infected from a prostitute and in revenge infected the rest. He paid more in order to have sex without condoms. SW-F-40

They take injecting drugs with one needle. SW-F-24-married

Given that HIV is an infection that is diagnosable only through a HIV test, SW respondents think that one of the best ways to protect themselves from infection is to ensure that everyone should be made to get regularly tested for HIV. People who should get tested even include those who provide direct services to others, such as doctors, nurses, policemen and taxi drivers. It is hard to say whether this is a perception that should be modified.

People who are connected to public catering [should get tested for HIV]. SW-F-40

Prisoners. SW-F-24-married

Healthcare workers. SW-F-30

Voluntary counseling and testing – Knowledge, practices and obstacles

The SWs referred to trust points in a positive manner, but noted negative aspects, such as the low quality of HIV tests and not always keeping confidentiality. Even when a person is registered under an anonymous code, he/she is required to show his/her passport if the person is diagnosed with having HIV, and a mark is made in the passport. The district police department is also informed, as well as the polyclinic and place of residence.

Some SWs admitted that they had never gone to get tested for HIV. The following reasons were mentioned:

I don't know where it's located or just don't have time for it. SW-F-30

I am not confident that they will correctly diagnosis HIV. SW-F-35-married

The other SWs had been tested for HIV and spoke of their experiences. Below are examples of voluntary and mandatory testing, which mention anonymous voluntary testing and sanitary standards being observed:

In 2009, a car approached our apartment building, and a neighbor came to me and said, "People are giving blood there to get tested for HIV. And they give you mascara [for getting tested]." Everyone was there in clean white gloves. It was all anonymous. They said that in 3 days, the results will come from America. They took the blood for the test in

2 minutes. They gave the telephone number. In 7 days, I called and told them my code and received my result. SW-F-40

I got tested half a year ago in Chor-Su at the AIDS Center when I wanted to get married. They didn't have a discussion with me. There were new gloves, and put new on new sheets. I came for the results, they gave me a certificate and I left, but I had to pay ten thousand. SW-F-21-married

Some SWs knew about the 3-6 month window period and of the importance of regularly getting tested for HIV. Others did not know about the window period.

After hearing these stories, the SWs who had never been tested expressed a desire to get tested for HIV anonymously at the AIDS Center but not at a polyclinic. Perhaps this type of information content and form of spreading information – through SWs sharing stories and experiences to other SWS – could be used on a wide scale as an information campaign that could involve not only SWs themselves, but also those who have sexual contact with them.

I would get tested with my husband. You can't tell from someone's outer appearance if the person's sick or not sick. SW-F-31-married and SW-F-35-married

The SWs believe that a serious barrier to seeking voluntary counseling and testing (VCT) services is the subsequent stigma and discrimination towards PLHIV and the possibility of forcing treatment upon them.

There's a lot of discrimination these days. It would be good if they "smothered" [eliminated] this discrimination. SW-F-37-married

My friend, a doctor, works at the AIDS Center. She is troubled by how treatment is voluntary and said that treatment should be compulsory. They should isolate them somewhere so that they didn't spread HIV. Why do they want to infect others? SW-F-31-married

Yes, for example, they can go to the dentist, and he won't know his status. Someone sick with HIV can go to any polyclinic and to a private clinic as well. They should have their own separate clinics. SW-F-34-married

The SWs think that there should be more points that are accessible in terms of distance and hours of operation, where individuals can receive consultations and get tested for HIV. They would also like the doctors to take special precautionary measures and use disinfected instruments, which SWs do not see at polyclinics, where precautionary measures are inadequate. SWs noted that they go to private clinics because of such conditions, but rarely because these services are very expensive.

There's probably a low salary at the polyclinics and, thus, they have such an attitude to their job. SW-F-35-married

I recently visited a private polyclinic. A general blood test costs 10 thousand som. SW-F-31-married

One of my acquaintances said that there's no forced treatment at the AIDS Center and that everything is free. SW-F-30

There's an Anonymous Room there. I go to the bazaar frequently and see young people come before their wedding, because your marriage can't get registered without test results. SW-F-31-married

Knowledge and experiences related to STIs

While the respondents did not talk about their own experiences with STIs (perhaps hiding such experiences), all the respondents demonstrated a sufficient level of knowledge about STIs. They know about gonorrhea, syphilis, and trichomoniasis, as well as that these diseases are curable,. They think that the only form of protection is by using male condoms, which are available in any store, pharmacy, trust points, and which are even given out by gynecologists.

I was involved in prostitution and didn't know that I had gonorrhea. I infected my husband. We went to the Chilanzar KVD [dermatology and venereology center], did all the tests, and got treated at the Sergeli KVD. Then my husband got infected with syphilis. And in the same way they cured him. We went there, as getting treated by a private doctor is expensive – near 200 thousand – and I don't earn that much each night. SW-F-37-married

I live near a textile plant hospital. There's a trust point there. I looked in and saw syringes and condoms. A guy went in and I saw that he left with syringes. SW-F-30

One of the SWs said that gonorrhea cannot be completely cured. She said that she was informed of this by a doctor.

It can only be mitigated and at any moment it can recommence, even because of a slight cold. SW-F-31-married

The SWs are not aware of the other methods of protection against STIs, including female condoms.

Some SWs mentioned a special cream that was used by a foreign client instead of a condom. Some also mentioned using a special sponge, if the client did not want to use a condom.

Knowing that a client did not want to use a condom, Mama Rosa made them put in a sponge there in order to not get infected, and afterwards they went into the bathroom and took it out. SW-F-24-married

Some SWs reported having acquired knowledge about STIs in school, from doctors, in maternity houses, and through Russian TV programs. They mentioned that in the maternity house, neighboring women in the ward found out about their STI.

Nowadays, in every school, they have a special subject starting from when they're 13 years old. My son is in school. SW-F-40

The boys and girls are separate. They teach the boys how to put on condoms. SW-F-24-married

The SWs admitted that when they go to the KVD for an examination, they try to “improve” their results – concealing the purpose of their visit.

They wash themselves with chlorine and toothpaste so that any infection wouldn't be detected. SW-F-24-married

One SW said that after being treated for any disease, people start to treat themselves in order not to incur extra expenses and to not face doctors' services that are of poor quality and unfriendly.

I went to the KVD. I was in a semi-shock state because of the pain. I went to a doctor. She was rude to me. It was very offensive. Then the head herself examined me and said that I have a cyst – not what the first doctor thought. SW-F-30

The SWs think that the services provided at the KVD are of a very low quality. This prevents them from seeking early and voluntary services at the KVD.

The atmosphere is unpleasant. There are barred windows like in prison. Their attitude to you is like their food. Suicides happen there. Girls cut their arms and hung themselves. SW-F-26, SW-F-24-married, SW-F-40

They make mistakes in their analyses. They said that I had an STI, but it turned out to be thrush. SW-F-31

They shove in mirrors of the biggest size. It hurts. They call you, “You cow, you bitch, you slut!” SW-F-24-married

I could not understand whom I saw in front of me at the KVD – a doctor or a butcher. SW-F-31

The SWs either get condoms themselves, or the “Mama Rosas” provide them with condoms.

The SWs think that information should be spread among the youth, since the accessibility level for information is low. They think that the youth have a frivolous attitude towards their own sexual health due to their hyper sexuality.

I have a son. He's a handsome guy. Girls throw themselves at him. I warn him, but he reassures me and says that he protects himself. SW-F-35-married

The SWs report that STI testing is highly available and available everywhere.

The SWs state that given the character of the services they provide, they need the anonymous services of gynecologists more so than knowledge about and services for HIV. So long as these services are not available, they have to turn to gynecologists that they personally know and receive their services sporadically, without regular monitoring of their health and STI.

They should take us without passports. SW-F-26 and SW-F-24-married

In principle, you can to go any for 5,000 som. SW-F-40

On the topic of condom use, the SWs mentioned situations and conditions when condoms are not used:

I have 3-4 clients of my own. I trust them. I know that they are married and have families. SW-F-26

There are various clients who do not understand that condoms are necessary and start to beat you. "You didn't give me what I want." They take away the money. SW-F-24-married

There are clients who pay more to have sex without condoms, and then you're all on the edge, you run to get tested for AIDS or go to the gynecologist. These sorts of people who want without are not less than 70%. SW-F-31 and SW-F-40

People lose control after using alcohol. SW-F-31-married

PWID are safe during sexual contact. They can do this for an hour or two but not come (not ejaculate). SW-F-24-married. (It should be noted that these "hour or two" can bring about worn spots and injuries on the partner, blood to blood contact and a high risk of contracting HIV.)

Men, even if they know, do not want to use condoms. They receive less pleasure. A woman can insist on what she wants, but the decision about using condoms is for the most part made by men. I mean, they're the ones who use them. You can't put it on with force. SW-F-31-married

There are many men and women, including prostitutes, who come to Tashkent. They are away from their families here, get infected, and "bring" it to their families. At the Kuiliuk bazaar, for example, it's terrible what happens there. SW-F-30

I worked for almost ten years at the Farkhad bazaar and it's the same there. SW-F-35-married

The SWs believe that the newcomers in particular greatly need knowledge and access to quality condoms.

A woman wanted to cheat on her husband. She had a condom with her that ripped during the sex. Then she was at the KVD to get treated from syphilis for four months.. SW-F-34-married

Information is needed on the location of trust points and AIDS Centers, as well as how to receive consultations over the telephone. Otherwise, individuals have to wait until outreach workers come with brochures and other materials. The SWs think that the printed materials should also be available for the clients in the locations where they come to seek the services of SWs.

I'd like to know where I could go to get tested where it will be anonymous. SW-F-26

They recommend that the population receive information through leaflets, booklets, and short videos on TV.

When they always tell you about the same thing, it stays in your memory. SW-F-30

The FGD participants also mentioned high risks of newcomers among SWs disappearing. The respondents feel that for the newcomers, slavery or murder are more dangerous than STIs. Thus, SWs should not only be informed about STIs, but should also be informed about the risks of slavery and disappearing.

One woman left for Tashkent to make money and disappeared without a trace. SW-F-35-married

I live on Shukhrat. I saw how a man took a girl to the entrance of the apartment building. They then left somewhere together. After some time, I saw her again but already with a different man. Five or six times in this way. At this pace, I guess, they would never even think about condoms! SW-F-31-married

They simply do not have the time to, for example, buy condoms and visit a polyclinic. They work from morning to night. SW-F-34-married

Injecting drugs - Knowledge, attitudes and practices

The SWs noted that the number of PWID has significantly decreased:

Five years ago, 5-6 people met in our entrance and they all shoot up with one syringe. Children ran around and played with them. There's nothing like this nowadays. SW-F-24-married and SW-F-40

I think many of them died of AIDS and from overdosing. SW-F-31

With each year, there are less drugs in Tashkent, and, thus, drug addicts are now drinking vodka. They're losing their human face and dying out. Heroin costs 25,000 som for a dose, while a liter of spirits costs 3,000 som. SW-F-40

As we can see from the SWs' stories, PWID are part of their social environment. Among these PWID are PLHIV.

My uncle was a drug addict. He died from an overdose. SW-F-35-married

My acquaintances and peers also used drugs. They died when they were young – when they were 20-22 years old. They would find them on the streets outside. SW-F-30

Three of my classmates died of drugs several years ago, too. SW-F-31-married

I know one family. The husband was a drug addict. He got infected with AIDS. He was stingy, didn't use condoms, and infected his wife. She's already been living eight years with this disease. SW-F-35-married

I had two neighbors. The older one was 36 years old, and the younger – 19. They used one needle. As a result, both died of cirrhosis of the liver. SW-F-34-married

The SWs think that addiction to injecting drugs can be cured only when the person himself really wants to be cured. This can be achieved if the people around the PWID help them form and support a will, purpose and meaning for life that will displace the craving for injecting drugs. Of course, money is also necessary, since it is much more difficult for poor PWID to lose their addiction.

If a person has the desire, then he can get cured. SW-F-31-married

Suggestion is necessary. Psychologists are necessary. SW-F-30

Money is the issue. One course of treatment for those who want to quit smoking costs 70 thousand. SW-F-31-married

There is a hospital in Sergeli where they treat drug addiction. The people who treat them from drug addiction, bring them drugs there themselves for money. SW-F-34-married

I have a friend who used drugs for about 5-6 years. But then she successfully got married. Her husband loves her a lot and takes care of her. I saw her recently. She stopped shooting up. She sometimes sniffs [drugs] and says "I let myself do this rarely now. I have another 'high' – my husband and child. A purpose for life has appeared." SW-F-40

We have a neighbor who got "cured" from injecting drugs. Now he has a child. He used to be so skinny. Now he even has a belly. He's rich and made a deal with the doctor and nurse that kept him from injecting drugs. He was always by his side. And the doctor would come and put him on the drip. SW-F-26

The SWs are ready and willing to help and support the PWID that are close to them, but want to know how. They suggest that some kind of group like Alcoholics Anonymous be created, where

PWID can receive psychological support and interact with each other. Such recommendations could be considered when organizing information and other campaigns – for example, for obtaining vitamins, medicine and syringes.

The SWs, additionally, think that when providing support for fighting addiction to injecting drugs, the following information should also be provided to PWID: “the address of the trust point, the telephone numbers, the types of services, and the guarantee of anonymity” (SW-F-26).

Information on TV, on the radio, in the press should say, “There’s an AIDS Center where you can get tested for HIV for free and anonymously. No one will find out anything.” And telephone numbers should always be provided. The words “FREE AND ANONYMOUS” should be written in big letters. And there are places for PWID, STIs, SWs. SW-F-40

KNOWLEDGE, ATTITUDES AND BEHAVIORAL PRACTICES REGARDING TB AMONG PWID

Knowledge related to TB

The PWID demonstrated a larger awareness than the SWs about TB, but their picture of knowledge and attitudes is also fragmentary.

TB is caused by the bacillus Kochii. In the past, in the beginning of 1919-20's, in the territory of the Russian empire, the former USSR, this disease was called "consumption". There can also be tuberculosis of the bones, and tuberculosis of the liver, and, generally, this bacillus can infect any organ of the human body. PWID-M-26-single

There is open and closed tuberculosis. The open form can infect people around you, while the closed form sits inside the person. PWID-M-single

BK+ means that the person is infectious. BK- means that the person can interact with people and not necessarily be isolated. PWID-M-26-married

The **main sources of information** about TB for PWID are discussions with those who are or were ill with TB or similar diseases, discussions with health providers (where they themselves were treated for TB), and printed materials, newspapers, and TV.

I had pleurisy. They drained out almost 2 liters of fluid. And when I was in the hospital, I heard about TB from people around me in the ward. PWID-M-single

I was being treated for TB. PWID-M-27-married

Doctors once came to us [and told us about TB]. PWID-M-22-single

On TV, they talked about hepatitis and tuberculosis. PWID-M-22-single

I was in a hospital for three months. I interacted with TB patients and found out and saw a lot in those three months. PWID-M-single

The PWID are aware of the following **TB symptoms**: cold symptoms, pleurisy, coughing, a persistent (2 weeks) body temperature of 39 degrees that is not brought down medicine, weight loss, weakness, and excessive sweating. All these symptoms can depend on the season, where they can worsen or emerge more frequently.

Tuberculosis looks simply like a cold in the beginning and people start to warm themselves up, which they shouldn't do. Many apply iodine and treat themselves with jam. When you're suspicious about having TB, you should really go immediately to the doctor. PWID-M-26-married

It can become more severe in the spring and autumn. PWID-M-24

Some PWID have doubts about the qualification level of doctors because of their inability to diagnose TB by examining symptoms. These doctors, in addition, need tomograms of the lungs. PWID also doubt the qualification levels of doctors who diagnose TB in a person who is not infected. According to PWID, if doctors cannot even diagnose TB through the indefinite symptoms in the early stage, then it is difficult to expect PWID and other MARPs to do so as well. Given this concern, perhaps PWID and other MARPs should be informed that, even in the case of a cold with lingering symptoms, they themselves should initiate seeking TB diagnosis services to find out if they are or are not ill with TB.

They were not able to detect tuberculosis in one PWID for 5 months. He had the lightest surface stage of tuberculosis. He stayed in a hospital for five months and the doctors could not figure out what the problem was. When he was already about to die, they examined him on a tomograph and only then determined it was TB. PWID-M-single

I know there was a case... they treated someone for TB for 3 months, and then they realized that it wasn't TB. It had just been some dark spot. As for how they detected the bacillus Kochii, only God knows. PWID-M-37-married

The respondents described people at risk of contracting TB or ill with TB as former prisoners, smokers, low-income people, those who have poor nutrition, those who can find a dose of heroin through any means possible, those in a constant state of depression, and those with a timid smile on his/her face who are hoping to live one more day.

Everyone is vulnerable to a disease like TB. More often the poor. Rarely among the rich and they can get treated, while the poor cannot. PWID-M-26-single

He goes in search of heroin – forgetting to have lunch. PWID-M-32-HIV

He is in a heavy psychological state. If I can't, for example, keep a family, if I don't have any earnings, if I can't do anything, then what I should be happy about? PWID-F-36

We know that there's not much [time] left for us. Everyday makes us glad. PWID-M-36-HIV

Causes and modes of TB transmission

The PWID mentioned the following causes that give rise to TB: poverty, pessimism and depression.

They cite the following modes of transmission: airborne transmission, sharing dishes, medical and cosmetic instruments in health and other facilities.

The bacillus is in every person. You can even simply catch the infection on a bus. It's mostly airborne. PWID-M-single

Not only like that. It is transmitted in any other way. I mean, it's a bacterium. When you eat, for example, the spoon isn't washed well, in a cafeteria outside, through dishes. PWID-M-26-single

I got sick recently. I got a cold. I got a general blood test. The nurse was sitting there. Her gloves were covered in blood. I said, "Could you at least wash your hands!" She said, "No, I'm not to wash them." And I said, "I'm going to go to a different doctor!" She didn't end up washing her hands. PWID-M-26-married

In one of the groups of PWID, there was a prevailing opinion that one of the modes of transmission is the intentional infection of another person, or from TBPs who are not careful about taking measures to protect people around them.

There are scoundrels who want to infect others if they get sick. He has an agenda: if I'm like this, then let others be like this, too. PWID-M-38

PWID living with HIV know that PLHIV have a weakened immune system and that they are particularly at risk of getting infected with any disease, including TB.

We are infected with HIV, we have a weak immune system, and we are afraid of getting TB. PWID-F-36-HIV

The following **TB prevention methods** were mentioned: "eating garlic," vaccination, a high-calorie diet and taking vitamins, regular checkups, not working in dusty environments, and protecting yourself from getting overly cold. Some PWID think that taking precautionary measures does not guarantee protection from TB.

No one can feel secure against TB. That's why in the US, every year, people get sent to get medical checkups from any job. They have medical insurance through which they all together go to the hospital and get medical exams – having their whole bodies checked. PWID-M-26-single

While the SWs were more concerned about protecting themselves from secondary infection, – i.e., from TBPs – the PWID spoke more about protecting themselves from items that could carry the bacteria.

One respondent mentioned that drug use creates more favorable conditions for developing TB disease, because after using drugs, you do not have an appetite. Other PWID think the other way around – that using drugs during critical conditions helps to maintain your health.

What's saving us is that we take drugs. If we didn't take drugs, then we'd have died long ago. Drugs maintain our immune system. PWID-M-36-HIV

When we were already dying, we thought that it was AIDS that was killing us. We decided, if it's AIDS that's killing us, we'll shoot up until we're dead, and we started to shoot up and shoot up, and we've still been living 4 years since then. Life continued for some reason. Maybe we're lucky. PWID-M-34-HIV

Needs, opportunities for and obstacles to acquiring knowledge

Like the SWs, the PWID said, “We want to know everything about TB.” Below are their opinions on their knowledge needs:

How can one get TB? How can one be cured from TB? PWID-M-22-single

Who can help me if, say, I get sick and I’m an orphan? PWID-M-single

I would like to learn more about the symptoms in detail. PWID-M-22-single

I have a small child and I need to know how to protect him. PWID-F-29-married

Where can we receive financial or food [product] support? PWID-M-32-HIV

The PWID said that any form of information is fine. What is important is that the information be interesting and that it not be frightening. They also want it to provide precautionary information, as well as provide hope and confidence in the cure.

It’s important to start it in school, but if they just talk, it’ll be boring. If they show some DVD, then it’ll be more interesting. They should show videos about how people die, how they suffer because of TB. PWID-M-single

If you only start showing things like that, there will be mass hysteria among the people! You don’t need to scare, but warn people. PWID-M-26-single

Materials should be tailored to age and gender. It should say that you need to get a fluorography done every half-year, for people to follow the regime, take care of their health, eat well and not smoke. PWID-M-26-single

Booklets should be disseminated in polyclinics and pharmacies. PWID-M-22-single

Some PWID think that informational materials on TB should be combined with materials on HIV, as the two infections are interrelated.

I know that if, say, I have AIDS and catch a cold, I will have dark spots in my lungs or my kidney will suffer, and I will die because of this. PWID-M-single

Seeking information and assistance

The PWID **seek assistance** when they are ill and know where to go to seek TB services. First they go to family and close relatives, then to district doctors, who refer them further to specialists.

I think that I would, first of all, consult my family, and then go to a physician. I'll get tests done at the polyclinic and then they'll refer you somewhere else further. PWID-M-single

You should first go to the district doctor. You should go to the pediatrician and he can then refer you further to where you should go, to a TB dispensary. PWID-M-26-married

They register you at the TB dispensary and call you to come regularly. They even call you on the phone and say that you need to come to take a sputum test every 3 months, get a fluorography done. The doctor in charge [of the case] takes control of your health. PWID-M-27-married

The PWID think special public programs should be developed to support TBPs.

Because the well-being of not only person, but also the whole population depends on this, you can say. PWID-M-26-single

Some PWID noted that monetary and food assistance are provided by the mahalla. They considered this one-shot assistance insignificant.

They give you hardly anything: 70 thousand. And what can you do with that?! PWID-M-26-single

I, for example, received a box a month. There was one kilogram of sugar and a little buckwheat. Some of these boxes don't get to those who are sick. They get "lost" somewhere. PWID-M-22-single

Some PWID think that **seeking treatment** is useful and that treatment should be sought in a timely manner, since TB can be cured during the early stage. In the PWID's experience, however, people usually delay seeking treatment, and the treatment can be long and is not always successful. Patients can experience psychological instability, depression and inclinations toward suicide/

I have a friend who was sick with TB. They put her in the hospital on Sofiiskii St. and even paid for it. She stayed there for 8 months. When they brought her, she was 1 m and 90 cm and weighed 38 kg. She now weighs 92 kg. She sticks to the regimen, she doesn't drink. The treatment helped. PWID-M-38

The main thing is not to lose heart. If you get sick and lose heart, that's bad. PWID-M-27-married

You should immediately go to the physician. "Treat yourself, son, is there raspberry jam at home?!" [This is what a mother tells her son, so that he'd treat himself from TB – mistakenly thinking that it's a cold. (Author's note)] But then the TB gets worse. PWID-M-22-single

You only go to the doctor when you're already in a critical state. PWID-F-29-married

Any disease has its initial, middle and final stages. There is also an ambulant stage when only a doctor's intervention helps. At the initial stage, a person doesn't notice the disease – thinking that it's just the flu – and then the condition worsens and the person starts to panic. "What's going on with me? I'll take these or those pills." The person starts to take pills him/herself. The symptoms lessen, the effect of the antibiotics pass, and the condition gets even worse, because the bacteria already compromised the person's immune system. PWID-M-26-single

People who have something wrong with their heads lay their hands on themselves [commit suicide]. I have a friend who didn't get sick with tuberculosis. He got sick with AIDS and he didn't know. And when he found out, he would get drunk, girls, bars, beer and then went and jumped off a roof. PWID-M-22-single

My dad had a friend. He served time in prison and got sick with tuberculosis there. At the end, they found him at home with cut veins. He got tired of the disease. The TB progressed. He probably decided, "Why am I torturing my old mother. It'll be better to quickly leave this life." PWID-M-37-married

Opportunities for and barriers to receiving consultations and treatment

The PWID, like the SWs, reported that diagnosis, consultations and treatment are available. They reported that you can seek and receive free services from polyclinics to TB dispensaries. There are other services that health providers may provide themselves or convince you to take.

If they detect it, nurses come to your house, because it's their job to check and control. PWID-M-27-married

The doctor says, "You need this. Not me! So please come yourself. We'll give you medicines for free. If you want to live, keep getting treated!" PWID-M-27-married

They regularly call you to the TB dispensary. They call you on the phone and say that you need to come to take a sputum test every 3 months and get a fluorography done. The doctor in charge (of the case) takes control of your health. PWID-M-27-married

A nurse explained how to take the pills and how to receive treatment. PWID-F-29-married

She gives you, for example, five packages of medicine and you need to give the empty packages back. Then they give you new medicine. PWID-M-27-married

Despite the availability of the services, the respondents mentioned the following obstacles:

- The **unexpected and unplanned expenditure of time and effort** for X-rays and doctor's exams

If they detect tuberculosis, then you have to put in the hospital. The doctor cannot hide it. PWID-M-26-married

- The **side-effects from the medicines taken** – “which make you go crazy” and **compromise your immunity**

They used to treat you using Russian methods, but now they use American methods. The Americans have some sort of different type of pills that make you go crazy. Even under the supervision of doctors, many do not take this Tubozit. I know of a case when they put it [this pill] on fire, and it kept burning and burning for a long time. Prisoners that were released and ended up in the hospital did this. I heard that they made “chifir” (strong black tea) with it. Tubosit makes you go crazy and lose your memory. A lot of people’s body’s do cannot tolerate taking it. PWID-M-single

My legs couldn’t walk after taking Tubozit. My joints hurt. You’re doing a crossword, you know the word, but you can’t remember it. PWID-M-22-single

- A **lack of money** and the need to pay for transportation, X-rays, analyses, medicine for treatment of concomitant disease, and other materials and medicine

The transportation expenses are high. You can, of course, walk 4-5 blocks, but you’ll do this once and another time, but the third time it’s unlikely you’ll go. PWID-M-36-HIV

They took 8 thousand for an X-ray and another 8 thousand for prescribing the medicines. All together, I spent more than 30 thousand, because blood was coming out my throat (coughing up blood). PWID-M-36-HIV

Sometimes the fluorography doesn’t work or they don’t have film, but if you pay them 7 thousand som, it works. PWID-F-36 and PWID-M-36-HIV

One injection costs 20 thousand, and you need to do it 10 times – which is in total 200 thousand som. They have syringes in the hospitals but you need to buy the drips yourself.

You spend around a million som. You need to buy food products, since what they give you is really bad, and you need a nourishing diet. PWID-M-27-married

- The **low quality of health services:** The PWID, as a whole, talk about the facilities where they sought services in a positive manner. However, they consider these services to be at times of low quality. Considering the low quality services, some PWID do not place blame but instead attempt to explain the situation.

They released one of our friends from prison early because of her diagnosis – active tuberculosis. As if she’s going to die anyway. They brought her to a TB dispensary for treatment and did tests, and it turned out that she didn’t have tuberculosis – she had AIDS. PWID-F-29 and PWID-F-23-SW

One patient had been treated for TB for several months, took a ton of drugs and got all the injections. And then, they did tests and said, “Sorry, it turns out that you didn’t have anything!” PWID-F-29

There are few specialists who go to work at polyclinics, because the pay is low. Huge lines of patients waiting to be received. There are big lines, and when you go in early, the doctors are still nice, but after hundred people, he already doesn’t care about you. There aren’t enough doctors. PWID-M-26-single

They are prescribing the wrong medicines. PWID-M-22-single

I went to the physician. She knocked on my back and asked, “What do you feel?” I had had a cup of strong chifir (strong tea) and my blood pressure had jumped, but she took my pressure and didn’t even ask me what I had eaten, what I had drunk. She just said that I had a high blood pressure and gave me antibiotics “out of a hat” [not based on anything], probably because she was young. PWID-M-27

- **Not always having adequate ideas about the possibility of being cured:** PWID’s beliefs on curing TB are diverse and range from “you can get cured” to “it’s not possible.” As they say, it all depends on the conditions and desire of the TBP to get cured.

Sometimes treatment lasts for years, but sometimes you can get cured within three months. PWID-M-single

Tuberculosis is a curable disease, but it doesn’t completely get cured. PWID-M-22-single

A lot depends on the person, too. If, for example, the person has a proper lifestyle – doesn’t drink, doesn’t smoke – then it’ll get treated. If the person has a weakened immune system, then it can lead to a lethal end. Many die of tuberculosis. PWID-M-27-married

The disease isn’t curable. It can temporarily be suppressed. PWID-M-26-single

It’s a terrible fatal disease. PWID-M-22-single

I was afraid to go to the hospital, because they don’t have treatment there. Each day they take away dead bodies from there. I stayed there two times. PWID-M-36-HIV

- **The PWID who had received treatment for TB know about DOTS.** The others do not know about the program, and some PWID living with HIV express their distrust of the program.

There is DOTS-1 and DOTS-2. DOTS-1 is for the initial mild stage. PWID-M-27-married

If you start early, the TB process can be suppressed in 3 months. PWID-M-single

After 3 months, you still have to get treated in the polyclinic for 8 months.

Confidentiality and stigma

Some PWID think that it is not possible to keep the diagnosis confidential. According to the PWID, this is not only due to the negligence of health providers, but also due to their various procedures. These procedures include patients being informed of their disease at their personal place of residence, patients having people come to disinfect their home, how PWID are registered, as well as the when people come to procedure for receiving social assistance. Other people are automatically involved when receiving social assistance, and these people do not understand the consequences of stigma and discrimination that occurs as a result of spreading information on individuals with TB.

The PWID mentioned instances when TBPs received treatment covertly in private clinics from doctors they personally knew in order not to lose their confidentiality and not be officially registered.

I get all my tests [analyses] done at a private polyclinic. PWID-M-27

There's no difference if you go to a private [clinic]; you need to pay anyway, whether it's at a private polyclinic or not. However, at a private facility, they will at least make the tests [analyses] properly. They don't look at you condescendingly. PWID-M-36-HIV

You can give a "hundred" [\$100] to the doctor and make a deal with him: "Make sure no one else finds out about this, just treat me, and that's all." You just pay him a hundred and that's it. Nowadays you can make a deal with anyone. PWID-M-22-single

A person asks him [a doctor], "Am I contagious or not?" The doctor finds out – running around [to the X-ray room, the lab, because he knows], you give him another hundred. PWID-M-22-single

According to the respondents, stigma and self-stigma are a result of fears of being infected by strangers or of infecting their own family members and close relatives with TB.

A TB patient is treated like a leper. They're afraid of bringing a cup of tea to you. PWID-M-26-married

If I'm sitting somewhere and cough a bit, I hear, "Hey you, don't cough, close your mouth!" PWID-M-36-HIV

A neighbor on the first floor was sick with "tubic" [TB], and almost no one interacted with him. PWID-M-36-HIV

One of our coworkers was hospitalized with TB and then everyone got checked in our mahalla after that because of him. PWID-M-32-HIV

If your neighbors find out that you're sick, they'll avoid you anyway. PWID-M-26-married and PWID-F-29-married

Sometimes even relatives avoid you. It depends on what kind of family you have. PWID-M-22-single

Some TB patients leave the hospital and make up some other reason for why he was in the hospital. However, they themselves try not to go near young children. PWID-M-26-married

As soon as you start coughing, people run away from you. PWID-F-36

And if they, God forbid, find out that he has HIV... PWID-M-34-HIV

One of my friends died 2 months ago of tuberculosis. His family wouldn't even let him in their house because of TB. He intentionally decided to overdose! He didn't have anything left – he didn't have any friends, no one at all. PWID-M-36-HIV

PWID with HIV are sure that the confidentiality of information about patients with TB and HIV is not being observed by health institutions or other institutions (medical-epidemiological services, polyclinic, district police department), They believe that health institutions are supposed to inform about the infection and its source.

KNOWLEDGE, ATTITUDES AND BEHAVIORAL PRACTICES REGARDING HIV/AIDS AMONG PWID

Knowledge and sources of information related to HIV/AIDS

All the PWID respondents have heard of and know about HIV, as well as how it can turn into AIDS, and fear HIV/AIDS. It is notable that some PWID think that HIV is not an infection, but a disease – that is, they directly identify HIV with AIDS. They also think that HIV is afraid of the “strength of its own infection”, or in other words\ they think that protective measures are not completely reliable and that it is not possible to cure HIV.

HIV and AIDS are the same thing. PWID-M-31

If you have HIV, you can still live longer. If you stick to a health lifestyle, you can have 5 years or 10 years or even up to 20 years. PWID-F-23-SW

HIV is a very scary disease; it’s a severe infection. PWID-F-35

You can have HIV for 6-8 years and not be aware of it, even if you are getting tests done. It always leads to AIDS. PWID-F-39

AIDS is terrible, not curable and fatal. PWID-F-31 and PWID-M-41

Some PWID noted that HIV is connected to a weakening of the immune system, the worsening of other diseases, or their transition into chronic forms. These chronic forms include cancerous forms.

Other PWID said that a vaccine that can cure HIV/AIDS has appeared, but think that this information had been mentioned in order to give hope to PLHIV and to provide them with support in their treatment.

They showed on NTV [a TV channel] how an HIV-infected girl was cured after getting vaccinated. Almost two years have passed. PWID-F-23-SW and PWID-M-27

Like the rabbit survived. They showed this in order to persuade people who are sick to go get treated. PWID-F-29 and PWID-F-23-SW

External HIV symptoms

The PWID think that one should not try to determine or guess another’s HIV status by only judging the person’s outer appearance. They think that it is only possible to suspect the presence of the infection in the last stage of the infection.

You get thin and look sick. PWID-F-31

I always want to go to sleep, even if I’m not in the last stage. PWID-F-39

You can only say through a blood test, and to do that you need to do several analyses. A lot of mistakes happen. Because of a mistake, a girl committed suicide. PWID-M-31

Sources of information on HIV/AIDS

Information on HIV is available for PWID from the following main sources (from the most frequent to the least):

Mostly through talking with people and through TV. PWID-M-34

I saw a video clip on an Uzbek channel. In this clip a person finds out at a health center that he has AIDS. His acquaintances turn away from. He doesn't know what to do. However, his wife gives him a helping hand. She herself doesn't get infected. PWID-F-29

I saw on TV that a woman got infected in a hospital, but in Russia. PWID-F-35

There's information in any polyclinic - on the walls, in booklets, etc. PWID-M-31

From neighbors, friends. I even read booklets at a hair salon. PWID-F-35 and PWID-F-28

I have acquaintances, who are infected with HIV. I interact with them. It's not the first year that they're sick [with HIV]. PWID-M-39

I heard [information] on a Uzbek radio station called Grand. PWID-M-34

People gave me booklets several times in the Gorky metro station. Girls distributed small brochures. PWID-M-31

I saw posters outside on the streets on December 1 – AIDS Day. PWID-F-29

The PWID mentioned a Russian TV channel that broadcasts TV programs on TB, HIV, smoking, and other topics.

They show a lot of such cases on NTV. PWID-F-31

On our television channels, information about HIV and everything connected with it is restricted. PWID-M-31

They talk a little about this disease here. They even say that it doesn't exist. PWID-M-27

Knowledge about risk groups

Considering that many people are HIV-positive, but would not guess that they are, PWID think that everyone is at risk of contracting HIV. Everyone at risk includes themselves, SWs, as well as foreigners, who they believe are more at risk of contracting HIV.

Many don't know, they don't get tested. They just live like that. PWID-M-31

First of all, you need it for yourself. PWID-F-39

If they controlled the coming of foreigners more. HIV and AIDS are more widespread in other countries. If their teeth start hurting here, he'll go to the dentist, and he can already infect our people there. PWID-M-31

The PWID particularly noted low-income people as an at-risk group for HIV

In order to have an immunity, you need to eat normally, and in order to eat, you need to earn a good amount of money! You have to eat at least once a day. How will people have an immunity if they eat poorly! This is one of the risk factors for HIV. PWID-F-23-SW

The PWID also emphasized that the most-at-risk group for contracting HIV consists of prisoners

I was in prison for eight years. They brought SWs infected with HIV there. They could infect others. PWID-F-29

Information and communicating with others in their community

The PWID avoid discussing HIV-related issues with their friends, partners, family members and close relatives, who do not inject drugs. If they do so at all, they only talk about HIV at the surface-level and do not go further into detail, as they consider it shameful and uncomfortable. They talk about HIV with people like them, with other PWID.

We have discussions with our sex partners. PWID-F-39

That it's possible to get infected. PWID-F-35

One of my acquaintances died of HIV. She was in the hospital. I gave her support and talked with her. PWID-F-39

It's shameful to talk about it with your relatives. PWID-F-35

You can talk about the basics with children. You don't need to go into details. PWID-F-35

Some PWID think that PLHIV could have something similar to associations and clubs, where they could discuss their plans and problems and advocate their interests through these

associations. These associations would also allow them to protect their rights for anonymous and free services that are guaranteed by the law.

Knowledge of HIV transmission routes and protection methods

All the PWID were aware of HIV/AIDS and of HIV transmission routes: using injecting drugs, sex, coming into contact with instruments that have infected blood on them at health facilities or tattoo parlors, or through contact with PLHIV. One of the respondents mentioned that untreated flu can turn into HIV.

Mostly via syringes used by drug addicts, and via sex. I know that mostly drug addicts have HIV. PWID-M-31

The largest proportion is through sex. PWID-M-31

Also during surgeries, and at the dentist's office. PWID-F-39

You catch the flu, which will result in complications and then turn to HIV/AIDS. PWID-F-39

In 2009-2011, when they came to the camp [for prisoners], they took blood [for analysis] using one needle for everyone. PWID-M-41

I went to the gynecologist in the city maternity house #2. She rinsed the mirror with water and that was it. I left and maybe another woman came in. PWID-F-39

It's not transmitted through the air. PWID-M-39

Some are afraid. Afraid to touch in order not to get sick. PWID-F-39

Some PWID-SWs said that in the past the main transmission route was injecting drug use, while now it is through SWs (PWID-F-29).

Only a few of the PWID mentioned the transmission route that goes from mother to child/fetus.

Some PWID were convinced that the infection may not necessarily be transmitted during sex.

If a woman is HIV positive a man may not get HIV from her. PWID-F-28

An acquaintance of mine met a girl and told her that he has HIV. They lived together for 3 years. They didn't protect themselves with condoms. Every three months or half a year they went to the doctor to get checked. He has positive results for HIV, but she has negative. PWID-M-27

HIV/AIDS prevention methods

Based on their knowledge of HIV transmission routes, the PWID note methods of prevention and protection from HIV. Prevention methods include condom use during sexual contact with clients or using your own syringes. Protection methods from HIV include abstinence from both.

Syringes should always be individually used. If having sexual contact with strangers, you should use condoms. PWID-M-31

The PWID mentioned latent symptoms and said that many people are infected, but are not yet aware of being infected. Some PWID believe that there are PLHIV that deliberately try to infect people who are not infected with HIV. They believe that these PLHIV either do not know about the criminal responsibility you must take for such actions, or knowingly do so out of spite, and the people they infect do not know about this law.

It happens sometimes that a person doesn't know that he is sick. PWID-F-39 and PWID-M-40

I heard that some intentionally infect others. PWID-F-31, PWID-F-39, PWID-F-33

So many people who are infected give blood, particularly during the window period (serological)! People do not trust the blood in blood transfusion stations and, thus, try to use their relatives' blood, but doctors do not allow relatives to give blood. PWID-M-41 and PWID-F-39

There is a criminal article [in the law] for this, but many simply don't know about it. PWID-M-31

The PWID are convinced that any protection methods are effective only if they are used in contact with PLHIV who do not seek to infect other people. These methods minimize risks rather than eliminating them.

There's no insurance, even if you use condom and your own syringe. PWID-F-39

There is always a risk – even if a small one. PWID-F-35

Few of the PWID mentioned the method of protecting a child by the mother not breastfeeding the child.

Voluntary counseling and testing – Knowledge and practices

While most of the PWID had heard of consultation points and trust points, others had not heard about them. After listening to the former PWID, these PWID simultaneously expressed both their distrust of and desire to use the services offered at these facilities. The former PWID mentioned that some of the trust points have closed and that others are too distant from places

where PWID reside. All the PWID articulated their distrust of these facilities maintaining their confidentiality.

I heard that in every district there are such centers, trust points. I have a friend, who gets syringes and condoms there. I was once offered to have my blood tested. PWID-M-30

Our workplace sent us to the polyclinic to get a checkup. I went voluntarily to one of these points and had my blood tested. PWID-F-28

They hold discussions about HIV and AIDS there. They sometimes organize meetings there. PWID-M-40

I got a fluorography done there, and my friend, also a PWID, received help finding a job. They gave him a referral to an employment agency. PWID-M-40

I doubt that anonymity is kept. That's why I've never gone to such points and don't know about them. PWID-F-31

At this point, I don't need it, but maybe I would go. PWID-M-30

I don't think good doctors work at these trust points. PWID-M-39

They would give you two syringes a day, and for that, I have to go to Chilanzar, Sergeli or Sputnik. The [transportation] fare is expensive nowadays. PWID-M-32-disabled

HIV testing – Knowledge and practices

Almost all the PWID have had their blood tested, but not all of them have been tested for HIV specifically. They said that blood tests are widely used when hiring new employees, enrolling students into educational institutions, before registering for marriage (syphilis and HIV tests), prior to having surgery, and are also done for voluntary testing for HIV.

Some PWID noted that in contrast to other blood tests, the test for HIV is, as a rule, anonymous with anonymous codes assigned to the analyses. This anonymity, however, is lost once the test shows the person to be HIV positive. Once this happens, he/she is required to show his passport and the health facility informs various other organizations about the new HIV case. The anonymity in the first stages, on the one hand, makes PWID more willing to get tested for HIV themselves and also makes them more willing to bring along their sexual partners and other PWID. The breach of confidentiality, on the other hand, is a barrier to seeking HIV testing services.

One guy went to an anonymous point, had his blood tested for HIV. The result was positive. They referred him from there to Botkin St. and told him to come there with his passport. You have to get registered with your passport in which they record your HIV status. PWID-M-39

One of my friends got his test done. Now they've begun dragging him around everywhere. PWID-M-39

The PWID believe that it is more difficult to persuade a family member to get tested for HIV.

When you have a family and children, there's more reticence. If you suggest it, you're the one that'll be blamed. PWID-F-31

The respondents' willingness to get tested for HIV is not solely due to the desire to know their own HIV status or that of their partners, but this willingness can also be partially explained by the need to protect the people around them as well as the high level of responsibility they have for their own health. The PWID believe you can get infected with HIV not only through a "bad" route, but also accidentally, such as when visiting the dentist's office. In this case, making the effort to get tested and know their status is about caring for people close to them and not a reason for suspicions.

First of all, you need it for yourself. PWID-F-39

I think they make everyone everywhere get tested these days. If you come by yourself, they ask, "Why did you come here to get tested? Do you know something about yourself [do you suspect something]?" I say, "No, I want to get checked for myself." They explained that it is anonymous and that you can tell your friends and acquaintances about this. They said that you need to protect yourself by using condoms and one-time use syringes. This was at a anonymous point by the metro stop Chilarzar. PWID-M-41

You can give them any name or your phone number instead of your name or they themselves assign you a number. PWID-M-31

They know you by your code and you know the code. You call, tell them your name, and find out the result. PWID-F-39

Before they register their marriage, people tend to get tested for everything. PWID-M-31

Before a surgery. PWID-F-35

If people are tested, HIV will spread less. If a person finds out that he is infected, he should automatically limit the number of people he interacts with. PWID-M-31

One of my acquaintances went to donate blood for someone who got into an accident. They found out she has HIV. The police came to her house and told her about this. Her husband beat her. Through an investigation, they found out that she had been infected at a dentist's office. PWID-F-27

There's no anonymity in our organizations. There are no secrets. PWID-M-39

I had my blood tested at the polyclinic #7. A week later, they [from the polyclinic] came to my neighbors and asked them, "Where is so-and-so? He's got AIDS." PWID-M-39

One girl has AIDS. She has children. My mother-in-law doesn't allow my child to play with the girl's children. She says that these children are AIDS-bearers. They tell all of Iunusabad about this. Even her neighbors constantly throw "dirt" at her [insult her] PWID-F-23

Sex workers and those who use their services often want to get checked for HIV, but are afraid that if they do so, everyone can find out (PWID-M-32-disabled). Some PWID, judging from the experiences of their acquaintances, are not sure about the quality of HIV tests and are not certain that the confidentiality of the test results will be assured, and thus avoid getting tested for HIV.

I, for example, am afraid. One of my friends had her blood tested for HIV. She was told that she is infected with HIV. She was pregnant. Twenty days later, she was informed that the diagnosis was incorrect. She was already in the maternity house. She had miscarried. PWID-F-23

The PWID respondents who did not have knowledge of or experiences with VCT services were doubtful that the service is free, and did not know where they could go to receive these counseling and testing services.

You think, "Where to go, who to go with, from whom to receive services, how much will it cost." PWID-F-29

Some PWID knew the address of VCT locations.

On the 6th block at Chilanazar, we have a hospital for HIV and people with TB. PWID-F-39

I had my blood tested at the AIDS Center at Chilanazar. PWID-M-34

I [had my blood tested] at Khamza and in the Iakasarai district. PWID-M-31

They checked when I had a surgery at the hospital. PWID-M-41 and PWID-F-35

In the Old City. There used to be a polyclinic there. PWID-F-28

Opportunities for and barriers to receiving information on HIV/AIDS

The PWID said that their knowledge level is low and that there are too few channels for receiving information.

There's very little of such information. PWID-M-32, PWID-F-28, PWID-F-29

My daughter is 15. She got a tattoo done. I asked her if she knew that you can get HIV [in that way]. She said, “No.” PWID-M-39

Comparing different sources of information and ways of delivering information, the PWID respondents came to the conclusion that the most attractive way to get information is through personal group discussions with specialists near where they live, work or study. Attendance should be mandatory. The group discussions should not take place with neighbors or in mahallas, where interaction with PWID is not advised. The discussions should be separated by gender, and should be conducted in a language that is appropriate for the participants. The use of appropriate terminology that is easily understood by all participants is also important.

Let them come themselves. PWID-F-39 and PWID-M-31

Let them come where we work. PWID-M-31

At educational institutions. PWID-M-30

For children, in particular. They’re just growing up, just starting their adult life. They should know. PWID-M-41

The neighbors won’t agree. They’ll say, “Why do you have suspicions about our mahalla? Do we have addicts or prostitutes or something?” PWID-M-45 and PWID-F-35

The respondents said that at these sorts of meetings and discussions, as well as on TV programs, only specialists speak and not PLHIV themselves. The respondents think that PLHIV themselves should also participate in such talk shows. Hearing the PLHIV speak will make the information more reliable, as well as minimize the stigma aimed towards PLHIV.

They don’t take people infected with HIV to work anywhere. They’re supposed to spread information, for example, at the local polyclinic – receiving a small salary. They’ll trust them more and interact with them. PWID-M-32-disabled

The PWID noted the following desirable channels for information on HIV/AIDS and other related issues. Unlike the SWs, who were against forms of information that aim to scare people, the PWID thought that it is important to have information that is intimidating. Perhaps for PWID in particular, the form and content of information should aim to arouse fear.

I would like to know in what cases and situations you can get infected. They only show [talk about] syringes and that’s it. They only hint at other methods [of transmission] or don’t say anything – especially about the healthcare facilities [where you can receive anonymous and free services]. PWID-M-40

[I’d like to] learn more about trust points and gain knowledge there. PWID-M-34 and PWID-F-35

Instead of always having TV ads about sanitary napkins, it'd be better to talk about this [information about HIV and everything connected with it]. They should distribute [printed materials] in the metro. PWID-M-41

[They should have] ads on banners, so that they constantly reminded people about this. PWID-M-39

They need some kind of frightful face and person. PWID-F-39

A scary needle with blood all the time [they show in informational materials]. PWID-F-35

Obstacles to obtaining knowledge on HIV/AIDS

The PWID said that the main obstacles for receiving consultations are that there are not enough VCT locations and trust points, and the ones that do exist are far away. Some VCT locations and trust points are located in polyclinics.

You'll see something in a polyclinic and not understand correctly. PWID-F-39

When you go into a normal polyclinic, everyone looks at you curiously. PWID-F-35

Some PWID mentioned that the text in booklets uses difficult language and terminology that is hard to understand, such as the word “immunodeficiency”. The text should be simple and understandable.

Knowledge about STIs and methods of protection

The PWID respondents are sufficiently aware of STIs. They named the following STIs; hepatitis C, syphilis, trichomoniasis, gonorrhea, and chlamydia. They also mentioned the following signs of STIs: discharge, itching, and redness.

I don't think there are such people who haven't heard about this. PWID-M-41

There's information at the polyclinics. You talk about STIs with each other. PWID-F-39

I have friends who caught “it.” You talk with them; you share the good and the bad. PWID-M-31

Gonorrhea cannot be detected in women. They are only carriers of the virus. Men, however, can't pee, on the third day. PWID-F-23

I heard that if you have syphilis, your nose will disappear. PWID-M-39 and PWID-F-23

All the PWIDs mentioned condoms as a method of protection against STIs.

Desire to receive information on STIs

The PWIDs think that little information on STIs is available for migrants who come from rural areas to the city, and these migrants use the services of SWs. PWIDs think that these migrants do not know about the danger of STIs, get infected, and then do not receive treatment or do not pay attention to the presence of the infection. Receiving treatment requires migrants to register their residence, is extremely costly in private clinics, or requires migrants to go to polyclinics in their own place of residence, where the presence of the infection may become known to family members, neighbors and acquaintances. Thus, some of those who are infected with an STI, including migrants, prefer ineffective self-treatment methods.

The migrants don't get treated, because they simply don't know about it. How could they find out about it? PWID-M-39

90 percent of prostitutes in Tashkent are now migrants from kishlaks [villages] - from Karsha, Namangan and Bukhara. They should get injections, but they just take pills that only temporarily dull the disease. PWID-M-32-disabled

Many of them are from Khorezm. They don't use condoms when they have sex. They sleep with people who are drunk. We see this all the time. PWID-F-29

The PWID respondents believe that information on STIs should be available not only in all medical/dental offices, in TV commercials, or in population newspapers, but should also be available in places where the migrants from rural areas work. The PWIDs noted that information is particularly important for describing in detail how STIs are transmitted.

There should be booklets. PWID-M-41

In other places [at schools, educational institutions, cafes] – without going into details, but providing a reminder, “Protect yourself!” PWID-M-41

Why aren't there video spots on TV that are even just 2-minutes long? Teenagers will see them. They'll be useful. PWID-M-34

There's no information on HIV or drug abuse in the papers or on the radio. PWID-F-31

There used to be a newspaper called “AIDS-Info,” but not anymore. PWID-M-41

In the newspaper Darakchi, there are some sorts of stories with hints, but no information. PWID-F-31

Experience having STIs

The PWID provided examples of their own experiences of having STIs and HIV, as well as experiences about receiving treatment for STIs. They provided examples of cases when the services were accessible and when they received the services without any problems.

One of my friends went to a gynecologist. They did a smear test and prescribed her with antibiotics. PWID-F-31

One of my acquaintances started dating a girl. She had lived with a drug addict before this. She gave him AIDS. She didn't know herself. They now live together. PWID-M-41

You can always get cured of STIs. Only AIDS isn't curable. PWID-F-31

Injecting drug use practices

Based on the information provided by PWIDs, we can make the following conclusions:

- While the number of PWIDs has significantly decreased in recent years, injecting drugs are still available and are being used in different places. These places range from homes to health facilities (the respondents even mentioned the Virology Institute), where injecting drugs are being used instead of or in addition to the medicines prescribed by doctors.

One is coughing, another has a temperature that's not going away. What should they do? Medicines don't do anything anyway. That's why they shoot up. What's important is money. It's [injecting drugs] are no problem to find. PWID-M-36-HIV

Right in the ward, patients with each other [use injecting drugs together]. PWID-F-36

- The following reasons exist for the decrease in the number of PWIDs:

Many have died. PWID-M-40

Heroin has become very expensive – 18,000 som for a fix. PWID-M-41

(Moderator's note: "Maybe I am mistaken, but it seemed like three FGD participants were under the influence of drugs even during the FGD. Signs included: incoherent and vague utterance of thoughts, slow responses, syntactic errors in the order of words in their sentences, and incomplete phrases.")

- The risk of getting arrested for purchasing injecting drugs is high due to the efficient work of those who are fighting against injecting drugs. PWIDs, however, lower this risk by bribing those who arrest them.

There is a criminal penalty for storing, using and distributing. Even if I bought it together with him and I distribute, even though we got it together. [That is, if he bought it and shared it with someone, this is considered distribution of injecting drugs.] PWID-M-36-HIV

They arrest you and you have to give 200-300 thousands on the spot right there. If you don't give it, then they'll put you in prison. And then it turns into 700 dollars, and then 1,000.

- The practice of sharing syringes, needles and solution has decreased, but continues due to the following reasons: a) the disposable syringes from the DOTS project have disappeared; b) heroin is very expensive and is easier to buy by pooling money together; and c) syringes and other equipment are being shared mainly by PLHIV, because as they are already infected with HIV, they are not as afraid of getting infected with other diseases, such as hepatitis C. The decrease in sharing injecting equipment is more attributable to PWID sometimes informing other PWID in advance if they have HIV, as opposed to being afraid of getting infected. This decrease in sharing injecting equipment is also due to PWID preferring to take doses alone without sharing doses with others, as each person gets a smaller amount when they share.

DOTS programs gave out disposable syringes. You can't use them a second time. When the rod goes in to the end, the needle comes straight out. PWID-M-41 and PWID-M-40

They try to give new syringes to everyone, but it doesn't always happen. PWID-F-35

We know that it's bad to use one syringe together, but when we have a fix, everything's OK. PWID-M-36-HIV

We pool our money together, because it's hard to get. You [use] with someone anyway. It rarely happens that you'll use all by yourself. PWID-M-41

Even if he says that he's infected with HIV, if I don't have a syringe, I'll shoot up with his syringe anyway, even if he told me in advance. I rinse it in boiling water. PWID-M-36-HIV

While he is away looking for a syringe somebody will take his dose. PWID-F-29

When there is a shortage in heroin or when PWID do not have enough money, PWID take *KDTs* ("crocodile") instead of heroin. This is prepared with medicine that contains codeine, which is sold over the counter in pharmacies.

You can easily get KDTs without a prescription at a pharmacy. 10 tablets cost about 4 thousand. They didn't use to have this medicine. PWID-M-36-HIV

They use a special method to prepare [this medicine]. PWID-F-36

Sometimes you think that the government is killing drug addicts intentionally. PWID-M-27

Drug rehabilitation – Experience and motivation

The PWID spoke of why people start to use and stop using injecting drugs. They said that very few people are rehabilitated from addiction, because many of the locations (such as friendly cabinets and trust points) run by non-governmental non-profit organizations where PWID tried to receive help are closed, and those that still exist are not very attractive. PWID also noted that people have also stopped using methadone substitution therapy due to negative opinions about the therapy.

You crave it in your head. PWID-F-39 and PWID-M-31

There's a saying that to kill a drug addiction you have to kill the addict himself. PWID-M-30

It's such a megalopolis, and there are only 60 something spots in the narcology center?! PWID-M-41

Two years ago, there was a program for drug addicts and people infected with HIV run by the Red Cross. It was at Chilanzar, in 15 blocks, at the narcology center. They gave methadone there. PWID-M-40, PWID-M-39, PWID-M-40

They gave out methadone, but this preparation was severely harmful for their health. They became morons stuffed with various preparations. PWID-F-35

Some PWID simply do not know that rehabilitation centers exist.

There are narcology centers. If drug addicts new where they could get treated, then everyone from Tashkent would go there. PWID-M-27

The PWID think that rehabilitation from addiction is possible only when the PWID really wants this. It is important to show PWID examples of people who successfully went through rehabilitation. Forced treatment might work initially, but once the forced period is finished, those who have a weak willpower may become even more strongly addicted. This is especially true of those who are depressed because of personal problems. Drug addiction treatment is expensive, torturous, humiliating, and similar to the cost of a dose of drugs, which instead brings pleasure. For such reasons, between injecting drugs and treatment, PWID choose to inject drugs.

You start shooting up and forget about all your problems. PWID-F-35

If they keep you for 10 days, then you'll "stick it out" [endure the withdrawal pains]. PWID-M-40

But when you leave, you start again. On the first day you leave. PWID-F-31 and PWID-M-41

A course of treatment costs 600,000 som. It's very expensive. PWID-M-41

There's a cleaning woman there [at the narcology center]. She receives a salary, but they force us to clean the corridors or the ward. They don't feel you well. It's worse there than in prison. PWID-M-41

If you are a drug addict or a prostitute, you can beat you. PWID-F-35 and PWID-F-28

They turn off the TV at 10 PM. If you start to ask for things, the attendant will tie you up. This is treatment?! PWID-F-31

I've been drinking black tea my whole life, but you're not allowed to drink it there. PWID-M-41

The PWID believe that seeking treatment should be voluntary, as forced treatment is ineffective.

Parents and relatives put you there. PWID-F-35

The police, with the court's sanction, pack you in there [forcibly send you to a narcology center]. PWID-M-40

The public prosecutor signs you up, they isolate you, and the doctor decides how long you'll be there for. PWID-M-40

The district police write you up, forcibly collect all documents and tests and send you to a narcology center. PWID-F-31

It's a place worse than a prison. PWID-F-39

Judging from the PWID's statements, it seems that PWID are placed in narcology centers in compliance with a certain legal order.

Desire to receive information on drug addiction treatment

The respondents think that there is currently no better place to receive information and consultations than in friendly cabinets and trust points (the PWID do not see a difference between the two). It is clear that this is because the PWID consider the outreach workers to be "one of their own" – just like them – in a way that they do view representatives of government and health facilities (such as the KVD, narcology center, and district polyclinics).

Knowledge of and practices related to individual protection methods

All the PWID know about condoms and receive information about them "everywhere": at school, on TV, and from parents.

Nevertheless, not all the PWID are sure that condoms protect against HIV. This is also the case with condoms that are used during casual sex with SWs, who, as a rule, have condoms with them.

I'll sleep [with a SW] without a condom for 50 thousand som and then three days later I'll pay the doctor 200 thousand. Why would I need that?! PWID-F-33

The women usually have condoms in these cases, while the men don't care in these situations. The woman particularly takes care not to get pregnant. PWID-M-39

As far as I know, they also talk about this in schools. They don't hide it. PWID-M-31

Nowadays, many definitely use condoms when they have casual sex. PWID-M-31 and PWID-M-30

It turns out that HIV, in any case, is transmitted through condoms. PWID-M-31

The PWID note that condoms are not being used in the following cases, including cases when men do not feel pleasure from sex while using condoms:

In a non-sober state. PWID-M-41

When they trust [when they shouldn't] or want to feel more pleasure. PWID-F-39

One gypsy woman goes up to a Russian woman and says, "Why do you have 3 children when I have 11?" The Russian woman says, "Use condoms." The gypsy woman says, "Dear, if I put a condom on your tongue, will you feel the taste of sugar?" PWID-M-41

In regards to condom use after using injecting drugs, the PWID think that after injecting drugs, they do not want sex. Injecting drugs alone are much better than sex. However, SWs noted, that some PWID have sex anyway, thus exposing themselves to a high risk of HIV infection.

You don't want to after drugs. PWID-M-41

While condom availability is high, PWID note that they are not always available either because of an absence of condoms, the price, or a refusal to sell condoms by the piece.

You go, for example, to a store. You think you'll get [them], but it's late, and they only have cigarettes and beer. The pharmacies are already closed. PWID-M-31

Gusarskie [condoms] cost 5,000 som for three pieces. PWID-M-41

Suggestions

The main need for the PWID is "where and how to take away the first withdrawal pains" (PWID-F-23).

Despite the seemingly inexpensive services for tests, consultations and free HIV test services, PWID perceived these services to be expensive.

I would like to get tested for STIs and other [infections] and receive any sort of treatment for free.

PWID-F-31

When I'm getting a blood test at the polyclinic, they require me to bring gloves, and they cost 1,000 som. And there are two rooms there. For each room, you need to bring gloves.

PWID-M-40

You need to bring your own syringe and your own gloves there. PWID-F-31

KNOWLEDGE, ATTITUDES AND BEHAVIORAL PRACTICES REGARDING TB AND HIV/AIDS AMONG PLHIV WHO HAVE TB

This section does not cover the knowledge, attitudes and practices regarding HIV/AIDS and TB of PLHIV, PWID and SWs, which was already described in previous sections. This section is focused on the knowledge, attitudes and practices of PLHIV who have TB – many of whom are or were PWID, SWs, or PLHIV without TB.

A particularity in the knowledge and attitudes regarding HIV or TB infections among women is based on women's beliefs that they have been infected by their husbands who are addicts or are infected with TB. This conclusion applies to all PLHIV and TBPs.

Knowledge, attitudes and practices regarding TB

The PLHIV who have TB have a sufficiently detailed level of knowledge about TB. They can specify information sources, symptoms, transmission routes, and ways of protecting others from TB, as well as have experiences with treatment that takes into account their HIV status.

A temperature for two weeks or more, a cough, weakness, sweating and night sweats, difficulty breathing, and then spitting blood, sputum of a specific color. PLHIV-TB+PWID-M

TB is curable. What's important is detect it early and adhering to the course of treatment assigned to you. PLHIV-TB+PWID-M

When I was in the Virology Institute [being treated for HIV], a doctor came every day to check up on me. You talk [with the doctor] and learn [information]. PLHIV-TB+PWID-M

A neighbor had a severe form of tuberculosis. They told him that it's too late to treat [the disease]. He lived a little while longer and then died. PLHIV-TB+PWID-M

Some of the PLHIV with TB stated that when someone has HIV and TB, the TB is first treated and then the antiretroviral therapy (ARVT) for HIV begins. They explained that the two treatments are separated because it is very hard for the body to simultaneously tolerate a lot of different medicines. Other PLHIV with TB talked about the simultaneous prescription of medicines for TB and HIV, and mentioned the poor tolerance of such a combination of treatments.

They took tests and told me to go to the Virology Institute after I've finished taking the tablets for tuberculosis. PLHIV-TB+PWID-M

They don't treat you for HIV when you're not yet cured of tuberculosis. They don't give you ARVT. PLHIV-TB+PWID-M

The medicines strongly affect your psychological condition. You become “inadequate.” One person broke all the mirrors in the washrooms and started to cut his veins. PLHIV-TB+PWID-M

They treat HIV and TB at the same time, but I refused to do so, because people hallucinate when they take the yellow pills. I saw a lot of people who died in the hospital because of this. PLHIV-TB+PWID-F

Since I am infected with HIV, I received Cotrimaxazol for free for 9 months at the RTH (Republican Tuberculosis Hospital), so that I wouldn't get pneumonia in addition to the tuberculosis. They prescribed me with DOTS medicines right away, vitamins, and isoniazid for the immune system. In the beginning, I took vitamin B-6. Then they put me on a glucose drip. PLHIV-TB+PWID-M

You have to stay in the hospital [the TB dispensary] for three months. Then for 9 months you have to receive supportive ARVT treatment and regularly take medicines, but these medicines are hard to tolerate. I'm incompatible with TV, but the ARVT course shouldn't be changed during the supportive phase in the TB dispensary. They replaced the medicines and I also took these pills periodically for the 9 months. PLHIV-TB+PWID-M

My doctor told me to start taking ARVT medicines. He said that if I don't take the pills, the TB will get even worse. I told that I wouldn't. He said, “Well, decide for yourself.” Straight from there they sent me to the Virology Institute. He said that I have to stay there. I told him all right but didn't stay there. I need to work. There's no one I can leave the kids with. PLHIV+TB-F

Some PLHIV mentioned instances when the doctors at the TB dispensary and the AIDS Center together paid attention to how their bodies reacted to the medicines for both diseases, and changed them when necessary.

I had to take [the pills for] both ARVT and DOTS. I felt sick. They connected over the phone with the AIDS Center and over the phone decided to change the TB medicines. Then they chose TB medicines that are compatible with the ARVT. PLHIV-TB+PWID-M

The PLHIV with TB said that information is only delivered occasionally in mass media and that the information is not complete, leading to distorted knowledge about TB, as in the cases cited below. Information is also at times only received after the fact, when the person already has the disease and when the disease is already in an advanced form.

My husband was sick and told me that after 30 years people will not get infected with tuberculosis, as if not to be afraid. But it turned out... PLHIV-TB+PWID-F

I found out about TB only from the head of the dispensary department. She explained everything to me in detail. The rest in the polyclinics, however, would rudely respond when I asked questions. PLHIV-TB+PWID-F

Thus, the PLHIV with TB, who know about the transmission routes, take measures not to infect people around them. Despite the fact that they are trying not to infect those around them, some PLHIV with TB (who are trying to earn a living and a means of subsistence) provide unofficial medical services to their acquaintances and neighbors or work in the service sector, where they have a lot of contact with clients.

I never give my glass, dish or cigarette to anyone, because I know [that I can infect people]. PLHIV-TB+PWID-M

I am a hairdresser by profession and a former healthcare worker. I graduated from a medical college – that is a technical school. So, I give people injections or put people on a drip. PLHIV-TB+PWID-F

Some of the PLHIV with TB know in detail the names of the medicines and the treatment regimen that they have been prescribed. Others do not know these details, either because of fatalistic attitudes or because of being indifferent to the treatment results. People in the former group are seeing quite successful results from the treatment, but those in the latter group are having unstable results. It is clear that PLHIV with TB should be more involved in the process of prescribing medicines and treatment regimens. Specifically, these medicines and treatment regimens should be discussed with the PLHIV with TB. Along with this, support for PLHIV with TB – material, psychological and social support from social workers – needs to be strengthened.

I've never received any kind of help anywhere from anyone. I think that TB is impossible to cure. You can only dull the disease. For treatment, you need to regularly – at least once a year – stay in the hospital. But I don't have money to stay in the hospital. You have to buy all the medicines yourself. PLHIV-TB+PWID-M

I'm not actually getting treated, but just receiving preventative treatment. It's very expensive. It's costly. I don't have a job. I haven't yet seen anything free besides the isoniazid. Why should I stay in the hospital when I can buy the medicine myself and do all the injections myself? In the hospital, you need to have meals, buy fat, you need milk. I don't have money just to even get to the hospital. PLHIV-TB+PWID-M and PLHIV-TB+PWID-M

Some of the PLHIV with TB follow the treatment regimen, but others do not due to various reasons. Reasons for not following the regimen include a lack of income, a lack of relatives who could help financially, as well as a lack of social support (including support from mahallas).

I don't even know where to go [for assistance]. When I stayed in the hospital, they said that every block is supposed to receive some sort of food ration. They said that they go to the apartments, call and say where they need to go to pick up their ration. I didn't get any call. Nothing. I went to the mahalla committee when I wanted to apply for the children's ration. They came to my place and saw that I have a dog at home and said, "You have enough to feed a dog, but don't have enough for your child?!" PLHIV-TB+PWID-F

The doctors at the TB dispensary said that I can receive food packages and material assistance from my mahalla? This is the first time I'm hearing about this. PLHIV-TB-M

I went to my mahalla and received an allowance. They gave 80 thousand each month. PLHIV-TB-F

The PLHIV said that because of the lack of income and social support, they are forced to resort to self-treatment and seek TB treatment services late, which leads to advanced forms of TB. They also emphasized that the health providers themselves do not detect TB early enough.

We were getting treated, my mom went to the pharmacy, to the family polyclinic. They prescribed me with injections. I injected them and injected them, and I saw that my temperature wasn't going away, I had nausea, I lost weight, I'm always lying down. My mom said, let's get your lungs checked. We went, got a fluorography done. The result was positive. I stayed in the hospital. PLHIV-TB-F

You take the pills and do the injections, but your temperature doesn't drop below 38 degrees. I had been getting three injections a day and took an enormous amount of pills before I went to the TB dispensary. PLHIV-TB-M

Every six months I inject myself with antibiotics – a complete course. PLHIV-TB+PWID-F

I get a cold from time to time, I suppress it with isoniazid. My temperature gets high, I feel that the process is starting. Especially in the fall and spring. I'm not really receiving treatment now. It's very expensive. It's costly. I don't have a job. PLHIV-TB+PWID-M

Some of the PLHIV with TB mentioned that treatment is not being made compulsory, but also that communication between treatment facilities inside and outside of prisons is not taking place. Others provided examples of coordination between facilities (not in prisons) in controlling the treatments. Yet other PLHIV with TB spoke of instances when treatment is not compulsory, and control over the TB treatment regimen is weak, which leads to interrupted treatment.

I left the hospital and after that I went to a specialist of infectious diseases and the specialist asked me, why me? They just told me, "This is your issue. Write an official refusal that you don't want to receive further treatment." I wrote a statement that I don't have any reason for complaints and that I refuse to get in-patient treatment, and that was all. PLHIV-TB+PWID-F

They (the polyclinic healthcare workers) don't ever come. And they don't even know that I came from prison with TB. PLHIV-TB+PWID-M

There is a DOTS room at the polyclinic. The doctor and nurse notes when I come every day and gives me the medicine. If I feel sick and can't come, the nurse calls and finds out what's wrong and brings the medicine or gives them to my parents to give to me. There's no compulsory treatment. But you need to take measures to receive the obligatory

treatment. Some people stop [the treatment] short or don't receive treatment. People even drink alcohol and take drugs in the hospitals that are not compatible with the medicines. PLHIV-TB+PWID-M

Some people don't want to take the pills and throw them in the bedside table. But if they find the pills in the bedside table or garbage can, then they start checking all the bedside tables and take measures to oblige people to take the medicines in front of the nurse. PLHIV-TB+PWID-M

Some PLHIV with TB mentioned that the hours of operation of TB dispensaries are inconvenient and that the conditions of in-patient facilities are unsatisfactory.

They only see people from 8 to 10 AM. Only for two hours and it's far from home. I went three times and spent money to get there only to stand in a line and pay 1.5 thousand som for an X-ray. PLHIV-TB+PWID-F

They don't do the procedures on time. They're always late. It's like a prison there. They say that the best treatment is sleep, but wake us up themselves at 8 o'clock. Their meals aren't good at all! And it's dirty in the hospital. It's not sanitary. They wash the corridor and ward with one rag. PLHIV-TB+PWID-F

Some PLHIV with TB mentioned that they are receiving medicine for DOTS once a week in a polyclinic or TB dispensary, and said that they cannot receive medicine on Saturdays and Sundays. Potential reasons may be that polyclinics are not open on weekends, or that the medicine supply comes in on Mondays to polyclinics and TB dispensaries.

Medicines are always available, but sometimes there's enough for 5 days, but not for Saturday and Sunday. And they'll only be available starting on Monday. It started getting like this recently. It didn't used to be like that. They were always available. PLHIV-TB+PWID-F

Those who were released from prison noted that in prison, there is strict control over TB detection and treatment through DOTS medicines, as well as over delivering information on VCT.

In prison, they came to us and said that you can go at any time, get your blood tested for free and anonymously. They said, "We have trust points." PLHIV-TB+PWID-F

They don't give any medicines to you into your hands. You have to take them there. They're strict about this. When you're free [from prison] they give medicine to you. When I got returned from prison, none of the healthcare workers came, though I returned with TB. I went myself. I needed preventative medicine. PLHIV-TB+PWID-M

The respondents know that they are not allowed to use alcohol or drugs, and that if they do, they can be discharged from the hospital. They know that if they stop using alcohol and/or drugs, they will be taken back into the hospital. Some of the PLHIV with TB mentioned many such cases.

I drink sometimes. I used to drink before, too. Sometimes I would go to a bar, take 200 grams of vodka and 2-3 mugs of beer. PLHIV-TB+PWID-M

They'll put him/her in the hospital again. They don't have the right to refuse this. There's a separate section there for those who had been discharged due to violations so that they don't bother those who want to properly receive treatment. PLHIV-TB+PWID-M

Some of the PLHIV with TB said that they received treatment services and medicines for TB and HIV for free, but not including syringes and IV sets. Others said that they paid for medicines either partially or in full. The respondents, additionally, said that the quality of food at the TB dispensary and Virology Institute is poor and that it is necessary to bring food in from elsewhere.

They had all the medicines for TB, but you needed to bring syringes, IV sets and other medicines yourself. I purchased riboxin and pyracetam myself, because they didn't have any. PLHIV-TB+PWID-M

In the beginning, they gave TB medicines for free in the hospital, but then they ran out, and we had to buy it ourselves. In the polyclinic, they only have isoniazid and that's it. PLHIV-TB+PWID-M

If you don't slip money into the nurses' hands, they won't even set you up on a drip. PLHIV-TB+PWID-F

The only problem was with the meals. If a healthy person stays there, then in a few months, he'll begin to have problems with his health from undernourishment. PLHIV-TB+PWID-M

Some of the PLHIV with TB mentioned that when there is a lack of X-ray film, they find the film for HIV patients. However, when there is a lack of medicine, staff sometimes try to hide this fact by using imitations of the treatment medicine, and threaten to not treat the patients if they do not go along with this pretense. In such a situation, one PLHIV with TB simply left the hospital in protest.

Journalists came to the Virology Institute. They never have medicine there (that's why I bought medicines ahead of time). A doctor there said to me, "The journalists are going to come now and they'll ask where your medicines are from! Tell the journalists that everything is OK." And I said, "Why will I say that everything is OK when we don't have anything here and I buy my medicines for half a million som." He said, "Then I won't make you not one of the medicines that you bought!" That's when I packed up my bags and went home. PLHIV-TB+PWID-M

Some patients understood that cleaning the hospital and grounds outside the hospital as being forced upon them, while others understood it as being necessary physical exercise.

They often organized cleaning days. The doctor would come himself and would show an example. Because when you just lie in your bed all the time, you start to develop congestion. The doctor, of course, doesn't call the severely sick patients who are not allowed to engage in physical labor. He knows everyone and who's in what condition. PLHIV-TB+PWID-M

During the course of treatment, some PLHIV with TB encountered signs of stigma from health providers.

At the city oncological center, the doctor yelled loudly, "People infected with HIV! They're all drug addicts!" PLHIV-TB+PWID-M

An urgent issue that PLHIV with TB cannot solve themselves in any way is that they do not have a separate room to live in. In addition, they do not have the possibility to live separately from the healthy members of their family and to visit them only when necessary. Perhaps "dormitories" should be made for PLHIV with TB in AIDS Centers or in other locations.

I need a separate room. My daughter lives at my brother's place currently. But if I didn't have a brother or had more than one child, she would have to live with me. I'd better live separately and be a "Sunday" mother. PLHIV-TB+PWID-F

Knowledge, attitudes and practices regarding HIV/AIDS

As is the case with TB, some PLHIV (who are, as a rule, people of adult age) have a sufficient level of knowledge about HIV/AIDS, such as its causes, pathogenesis, treatment, methods of protecting others against it, etc.

HIV is the "human immunodeficiency virus." The virus affects the immune system of a person and the CD4 T-lymphocytes. It penetrates the cell receptors and replicate there.

AIDS is the final stage of HIV, when the immune system has been destroyed and several diseases develop simultaneously, including opportunistic diseases, and sometimes the treatment for one disease is not compatible with the medicines for the treatment of another disease. Among these diseases are tuberculosis, pneumonia, toxoplasmosis, as well as cancers, sarcoma, etc. PLHIV-TB+PWID-M

Sources of information on HIV/AIDS include the following: virologists, PLHIV themselves, and, especially, the Internet. Through the Internet, some PLHIV are not only communicating with patients like themselves who reside outside Uzbekistan, but also with various non-governmental international organizations.

I've subscribed to mailing lists of various non-governmental international organizations. Particularly in the CIS, there are virtual communities for people infected with HIV. PLHIV-TB+PWID-M

Information on HIV testing is also available. The PLHIV who have TB demonstrate this knowledge.

EIA is enzyme immunoassay. If it shows a positive result, then you don't know yet if the person has HIV. You need to do an immunoblot. If the immunoblot confirms the result, then it means that the person has HIV, because there are sometimes different conditions of hepatitis C that sometimes give false-positive results. There's a window period (serological) from 3 to 6 months. You have to wait for at least 2-3 months while antibodies are produced. During these three months, you have to maintain an absolutely proper healthy lifestyle. That's why there are consultations where doctors conduct pre-test consultations. PLHIV-TB+PWID-M

Some of the PLHIV with TB described in detail their experience of getting tested for HIV, including the stages of and motives for testing (random and irregular testing).

I was sick for a long time. I got tested for particular infections at the polyclinic and they didn't detect anything. I have a neighbor who is a doctor. She's an elderly woman with experience. She told me, "Go get tested for HIV at the AIDS Center." I went to get tested anonymously at the Republican AIDS Center. There was a trust point there. I got a blood test done and there was a seropositive result. After that, I got tested 3 more times. They did the last analysis for a really long time. It seems that they were double checking and triple checking. PLHIV-TB+PWID-M

PLHIV as well as their relatives and acquaintances sometimes react to test results with relative composure, or sometimes react with panic. Psychologists at the AIDS Center provide help in the latter cases.

There's a psychologist there helping patients, because there have been many cases when a drug addict found out that he has HIV and then overdosed and died. My girlfriend left me after she found out. PLHIV-TB+PWID-M

Some of the PLHIV with TB noted that there is estimated to be a high availability of syringes and condoms.

Volunteers bring free syringes and condoms after you call them once. PLHIV-TB+PWID-M

Some of the PLHIV with TB mentioned the attention paid towards themselves and the HIV by the healthcare workers at the AIDS center.

They know that it's HIV. They say that you need to receive treatment, they try and persuade you. They say that you've been sick for more than 5 years and you need to support your immune system if you want to live longer. PLHIV-TB+PWID-F

Knowledge, attitudes and practices regarding STIs and injecting drug use

PLHIV who have TB have a more extensive level of knowledge about STIs than do the PWID and SWs who do not have HIV. Unlike the PWID and SWs who do not have HIV, the PLHIV with TB mentioned swelling of lymph nodes in the groin area among the symptoms of STIs. Perhaps they noted this symptom because it is similar to symptoms of HIV/AIDS.

Unlike the PWID and SWs, the PLHIV with TB mentioned the domestic modes of STI transmission, such as sharing personal hygiene products, dishes, clothes, etc.

Among the various sources of detailed information on STIs, the PLHIV with TB noted, in particular, that the information they received was from the AIDS Center and from the various other events that the center has organized. There are no barriers to obtaining knowledge about STIs for the PLHIV with TB, but some mention that they have been noticing fewer booklets and brochures. Others mentioned that people even bring such materials to their homes.

A resolution was issued that materials need to be approved prior to printing. Now there are no booklets around. They would be useful for young people. PLHIV-TB+PWID-M

The practices related to injecting drug use and sex that the PLHIV with TB described are similar to those of PLHIV without TB (see section on Knowledge, attitudes and behavioral practices among PLHIV). Some of the PLHIV with TB suggest that posters for PWID should have text similar to the following: “Do you really value your health (life) less than a syringe or condom?!”

KNOWLEDGE, ATTITUDES AND BEHAVIORAL PRACTICES REGARDING TB AND HIV/AIDS AMONG PLHIV

General knowledge about HIV/AIDS and knowledge needs

This section is specific to PWID or SWs who are PLHIV. It should be noted from the beginning that among the PLHIV, there are a number of those who worked or work in the service sphere (salespeople, cooks, waitresses) as PLHIV and those who even became SWs after being informed of their HIV status.

I used to work as a cook but I lost that job. Now I work as a prostitute. I need to feed my family somehow. I practice safe sex; I don't want to infect my clients. PLHIV+SW-F-34

The PLHIV have quite an extensive knowledge about HIV/AIDS. They know what HIV is, how it differs from AIDS, what transmission routes exist (including parenteral transmission), what methods they can use to protect themselves and particularly people around them from getting HIV, and the location of facilities that are supposed to provide VCT, treatment, syringes and condoms. In the present study, PLHIV exchanged their opinions on the quality of these services, the ARVT process, the medicines and foods that support the immune system, what certain CD counts indicate, and what to do in the case of certain CD counts.

The PLHIV mentioned a large number of sources for receiving information on HIV: TV, radio, Internet, brochures, booklets, and doctors from the AIDS Center and the Virology Institute. They also shared, of course, the main sources of receiving information on HIV, which are their own experiences and the experiences of the groups at risk for HIV.

A person with HIV status pays attention to everything related to HIV. FGD-PLHIV+SW-F-28-son with HIV

Everybody talks about HIV and AIDS. FGD-PLHIV+PWID-M-32

In regards to such information sources as doctors, the PLHIV mentioned messages about HIV that they received from doctors at the Virology Institute. Among these messages, they mentioned hearing information that made them doubt other previously received information and the reliability of the sources.

I once happened to visit the Republican Virology Institute. There, I heard from an experienced surgeon that AIDS is also spread through the air. FGD-PLHIV+PWID-F-28

An infectious diseases specialist at the AIDS Center had a discussion with me the very first time. That's when I found out about HIV for the first time. He also talked about TB. FGD-PLHIV+SW-F-38

The SWs provided examples of women with HIV who had sex with cohabitants for a long period of time without using condoms and the cohabitants did not get infected. Such cases made them think that HIV is not always transmitted through sex.

Regardless, the HIV protection methods that PLHIV noted are, first of all, condoms and not sharing syringes with PLHIV when injecting drugs. Like the PWID, PLHIV prefer to use injecting drugs with their own syringes. The PLHIV also mentioned such protection methods as avoiding contact with the blood of PLHIV as well as the instruments in homes and health facilities that may have had contact with the HIV-infected blood in the home.

First of all, when I found out about my HIV status, I got interested about how this can affect my family members. They explained to me that I need to use separate personal hygiene products, a separate toothbrush, etc. FGD-PLHIV+PWID-F-30

Regarding the prevention of HIV transmission to the child of a woman who is HIV positive and pregnant, the PLHIV stated that the safest way to deliver the child is through a Caesarian section, and that other ways that a child could get infected depend on specific circumstances.

My friend told me that the maternity house #9 at Chilanzar is always getting closed, because a lot of people infected with HIV give birth there. I started asking my doctors. They said that I can give birth, but through a C-section. FGD-PLHIV+SW-F-28-son with HIV

The PLHIV are sure that the HIV status of a person cannot be determined by looking at his/her outer appearance, that it can only be determined through an EIA (enzyme immunoassay), and that even this test does not always provide accurate results. The PLHIV who are SWs said that a person with TB symptoms is very likely to have HIV.

The PLHIV said that TB and hepatitis C are the most serious concomitant diseases that most frequently affect PLHIV.

The PLHIV mentioned the following risk groups: “us ourselves”, PWID SWs and “any person.” They said that everyone, without any exceptions, needs to get regularly checked for HIV. They said this because PLHIV are having more and more contact, including in the service sector (restaurants, cafes, sales), with healthy people.

Though they are informed about HIV/AIDS, the PLHIV would like to increase their knowledge, as they have a strong desire to strive to live and hope for living together without despair and an expectation of death. The PLHIV need psychological support to maintain this sense of hope, support that AIDS specialists have been providing in one way or another.

HIV sooner or later leads to AIDS. FGD-PLHIV+PWID-F-30

HIV or AIDS is death – like when you’re walking on the street and all of a sudden a car knocks you down! FGD-PLHIV+PWID-M-32

What’s the difference, when you’re going to die?! FGD-PLHIV+PWID-M-32

I’d like to live longer. FGD-PLHIV+PWID-F-28

Hope. Only hope. What they do there, the scientists, I want to know about this. FGD-F-PLHIV+SW-38

The most important message that PLHIV need, a message that they have already somewhat been receiving, is that an individual can live a long life with HIV. A convincing argument for this is the fate of real people more so than the words of doctors. The PLHIV, in fact, have already been hearing about PLHIV who have been living more than 10 years since learning of their HIV status. These “rumors” need to be supported.

I know people who've been living for 15 years. FGD-PLHIV+SW-F-38

My sister used to work at hospital, and she told me about a woman with HIV who had been coming to them for 15 years, being examined regularly, continuing to live. There is also a guy with HIV who would still indulge in alcohol and drugs once a year, - though it's forbidden, - and then continue his treatment; he's been doing this for 12 years already. FGD-PLHIV+PWID-M

Although the PLHIV know a lot about HIV/AIDS and know significantly more than people who are not living with HIV, they think that there is not enough information presented in mass media for the general population.

There's very little basic information. FGD-PLHIV+PWID-F-30

When a person falls into such a situation, he then more or less starts to get interested – what, why. When it doesn't concern you, you think, maybe it'll come, maybe it'll pass. FGD-PLHIV+PWID-M

Unsystematic and incomplete information about HIV and TB is the result of a lack of visual diagrams and decision making algorithms, such as the “10 Steps” algorithm, that lay out what to do in certain cases. It is clear that these types of information should be used in information campaigns and distributed through AIDS Centers, so that PLHIV could possess such material at home, when they get pregnant, and in other situations.

Gynecologists should tell us everything related to HIV as well as children before pregnancy and after [childbirth]. FGD-PLHIV+PWID-F

The PLHIV noted that there is little information available at the district polyclinics as well as outside on the streets.

They don't even talk about this topic in polyclinics. We gained more knowledge from our infectious disease specialists than now we go to the polyclinic. Not saying anything, they just give you the ARVT and that's all. FGD-F-PLHIV+SW-28-son with HIV and FGD-F-PLHIV+SW-38

The PLHIV think that groups or clubs for PLHIV are needed. Such groups or clubs would provide a space for PLHIV to support each other and share their experiences with each other. They could meet in “anonymous rooms” or be supported by NGOs. They say that NGOs “care about us more” (PLHIV+SW).

We understand each other better. FGD-F-PLHIV+SW-38

We wouldn't point fingers at each other if we had our own community. FGD-F-PLHIV+SW-28-son with HIV

Voluntary counseling and testing – Knowledge and practices

Some of the PLHIV said that they had never heard of VCT. This contradicted the fact that all of the PLHIV have used the services of the AIDS Centers, trust points, and friendly cabinets, and had been provided with consultations, testing, syringes and condoms. It seems that most likely the respondents are not familiar with the term voluntary counseling and testing, or VCT.

The PLHIV spoke about VCT services in an unclear and ambiguous manner. On the one hand, they said that they in one way or another receive consultations and testing, but on the other hand, they also said that there are obstacles to receiving VCT services. Specifically, they mentioned the following:

- An insufficiently sensitive attitude and a lack of “human” skills when informing people about their HIV status at the AIDS Center

I was diagnosed with HIV after having been at a hospital. I came to the AIDS Center, and they asked me, “Come tomorrow.” I came. Some psychologist talked about something for half an hour. I told him, “I don't need words. I need a doctor.” The doctor wasn't there. They gave me papers to sign. “If you infect someone else, they'll give you 10 years. Everyone, leave, you're registered.” They kicked us out. At the polyclinic, a doctor said, you have HIV. They treat you where you were sent. FGD-PLHIV+PWID-M-32

She told me about my HIV status straight into my forehead. She just killed me. This is everything she said: “Here we have brochures. Have a read. If you infect others, they can put you in jail.” FGD-F-PLHIV+SW-38

- No access to consultations at district polyclinics.

They don't let us in; they don't take us there. FGD-PLHIV+PWID-F-32

- The risk of losing their confidentiality at health facilities of all levels that share data with each other about PLHIV, which is done as a preventive measure to protect people who do not have HIV and to also monitor the situation of PLHIV

After the maternity house, all the polyclinics know that I have HIV, and that I work now as a waitress. Everyone even at work knows. The person who takes blood [didn't specify

the facility] from my child informs everyone that my family members may also have HIV. FGD-PLHIV+PWID-F

When I got into an accident, they brought me to the traumatology center. The next day, everyone there knew that I have HIV. They said that you supposedly have to tell everyone in advance, so that no one would use my things. FGD-PLHIV+PWID-F-30

I would trust them if it were anonymous. I know a lot of them. If I need some sort of information, I can go to them. FGD-PLHIV+PWID-F-30

I don't need this. People are different, I'm afraid [of babbling]. FGD-PLHIV+PWID-F and FGD-PLHIV+PWID-M

- The stigma level towards PLHIV is still high, though it is clearly decreasing. People have started to treat PLHIV with more tolerance, and do not always fire them because of their HIV positive status. Instead, they sometimes help them to keep their job. Family members and acquaintances treat them with understanding, because they see the person and not the infection in front of them. In other cases, when PLHIV and people at risk are considered in an abstract manner, people have a very cruel attitude towards them. This is especially true among those who were infected through contact with SWs. PLHIV are being treated cruelly, especially by those who have been infected after a contact with SWs. It is clear that in order to decrease the level of stigma, information must be humanized and personalized through the prism of a concrete, real person fate.

My boss didn't want to let me go. He said that he wanted me to stay, that he's satisfied with my work. He said, "Let's get a certificate done for money that you don't have HIV." I worked as a waitress. FGD-PLHIV+SW-F-38

People get scared. I got fired from my first job. I'm still at my second job. I'm hiding that I have HIV. FGD-PLHIV+PWID-F-30

Some laugh at you. FGD-PLHIV+PWID-F-26

Some sympathize and bother you with recipes of folk medicines. FGD-PLHIV+PWID-F

Intense discrimination begins when they talk about HIV and PWID. FGD-PLHIV+PWID-F-30 and FGD-PLHIV+PWID-F-32

Some think that they should create a special island and send all people infected with HIV there. My friend recently found out in prison that he has HIV. And he openly told his friends that he's going to deliberately infect all these "sluts." FGD-F-PLHIV+SW-38

The PLHIV have been tested voluntarily more than once, including repeat tests done in the same and different health facilities in order to check the reliability of the previous test. In some facilities, the tests were anonymous with codes assigned (the AIDS Center), and in others the tests were not anonymous (maternity houses).

You want to believe that it's a mistake. FGD-PLHIV+PWID-M-32

I didn't believe it and got tested several times. FGD-PLHIV+PWID-F-32

One of my acquaintances who is also a healthcare worker explained it to me like this. It's like a stray bullet. The first time you get tested, you're near, and time passes, and the bullet may end up on the target. FGD-PLHIV+PWID-M

I got tested four times. One time it showed positive and three times negative. FGD-PLHIV+PWID-F

Practices related to seeking and adhering to treatment

Some PLHIV receive supportive and supplementary treatment, and others refuse to receive treatment. People in a third group periodically stop taking treatment and try to replace treatment with a diverse and healthy diet that is rich in vitamins. The reasons are as follows.

The conditions at the Virology Institute are terrible. The premises are in a poor state. They give you little attention. There isn't any medicine. My husband is there. When they found HIV in me, I said, "Are you going to send me to that institute? I was there. I know that they don't have any treatment available." You feel sorry for everyone there – not washed, unshaven... Do they take them there not for quality but for quantity? PLHIV+SW-F-34

I found out three years ago that I have HIV. I'm not receiving treatment, because I have a lot of acquaintances that got worse from receiving treatment. FGD-PLHIV+PWID-F-28

They opened a room for HIV patients. They were being seen by an ENT [ear, nose and throat] doctor, cardiologist and a dentist. They renovated the room well, but didn't always take patients. They only took patients when they wanted to. And now, it's basically closed. FGD-PLHIV+PWID-M-32

The PLHIV did not give one straightforward opinion about ARVT at the AIDS Center and Virology Institute. Some PLHIV said that treatment is voluntary, that they receive medicines in a timely fashion, and that ARVT helps them live a longer life. Other PLHIV said that treatment is forced, that medicines and CD count tests are not always available, that there are long periods when medicines are unavailable (which creates long breaks in the treatment course), and that they have to purchase medicine.

This treatment increases the length of your life. FGD-PLHIV+PWID-F-30

Sometimes there are interruptions in the supply of medicine. Sometimes of the 3 preparations you take, one of them is sometimes not available. Lamivudine wasn't available last time. And they replaced it with abacavir. I borrowed it, in a sense, and then gave it back. FGD-PLHIV+SW-F-28

They [doctors at the Virology Institute] tell you honestly, “If you stay in the hospital, they’ll have nothing to treat you with and nothing to feed you with.” You’ll buy everything yourself. We stayed there for 8 days and didn’t receive treatment. We started to deal with the MoH [Ministry of Health] about it and everything’s now seemingly in order. The interruptions in the supply of medicines were connected with customs. They told them to be closed if they can’t provide people [with medicine]. If they can’t ensure people with medicine, then they shouldn’t have prescribed them. FGD-PLHIV+SW-F-38

They have medicines for ARVT, but not always. They don’t have this or that preparation. FGD-PLHIV+PWID-M-32

The PLHIV said that access to treatment for common diseases (not HIV/AIDS) is difficult and irregular because of their HIV status. They also noted the significant amount of time and money that is spent for transportation to health facilities.

In the ambulance, they told me, “We’re not going to put you on a drip. We know about you.” PLHIV+SW-F-23

Everywhere they refuse to treat your disease and send you to the AIDS Center. FGD-PLHIV+PWID-F

The AIDS Center doesn’t take patients for treatment without having X-rays of their lungs. In one place, something is broken, in another place they don’t have film, and they don’t always have the reagents for the tests. You have to go to a private clinic for an X-Ray and it costs 50 thousand there. FGD-PLHIV+PWID-F-26 and FGD-PLHIV+PWID-F-32

The PLHIV noted that some of them spend all the money they have for the injections and other procedures at the Virology Institute.

Only when you give money do they give you an injection. FGD-PLHIV+PWID-F-32

Needs

The PLHIV very much appreciate when people approach them in an actively friendly, psychologically sensitive manner. When such an attitude is missing, they relate the people to those who show indifference in the face of suicide.

They treat me as if am not a human being. FGD-PLHIV+PWID-F-32

You are killing yourself by being depressed when, instead of assistance, you see its imitation. FGD-PLHIV+PWID-F-32

I used to have plans, I had goals for my life. Now I don’t have any of that. FGD-PLHIV+PWID-M

The PLHIV think that psychological support is not only about treating diseases, but also, importantly, related to eliminating the discrimination that they face due to their disease and increasing involvement in the life and occupations of “ordinary” people. For this, they need consultations and support from lawyers, who can help them find employment and ensure that their HIV status does not act as an obstacle. PLHIV with children need benefits in order secure a place in kindergartens for their children.

I know that I only have a few years left, but this doesn't mean that I should lay my hands on myself. You shouldn't just live in an expectation to die, but to live. FGD-PLHIV+PWID-F-30

If, in the past, we could go to another country to work, we can't. You have to get a medical checkup and then they'll deport you right way. It's discrimination. FGD-PLHIV+PWID-F-30

I would like to study at a medical college. But they won't take me, because of my status. Another person with HIV will give 5 thousand dollars and the next day she'll be studying about HIV. FGD-PLHIV+PWID-F

PLHIV do not only need help from lawyers, but also need assistance with issues regarding employment and receiving free treatment. Additionally, some SWs living with HIV need legal protection from their cohabitants. These cohabitants or pimps blackmail SWs living with HIV, where they give away all their money, threaten to tell everyone about their HIV status, and beat them because of their HIV status and put them at risk of getting infected – forcing them to go to rough areas to earn money. SWs with PLHIV also need legal protection from the police, who “catch” them when they are working, rape them, and put themselves at risk of contracting HIV.

Girls went to the clients and served them in their cars. And they [the police] beat them and raped them – 4-5 policemen at a time. The girls then couldn't work for a week and the Mama Rosas demanded money of them for being absent from work. PLHIV+SW-F-23

Some PLHIV emphasized that they need to hide their HIV status in different ways when they go to other countries. They think that they should receive legal support for going to countries that refuse entry to PLHIV and discriminate them in this way.

My friend died of HIV in Moscow. She was infected with here, went to Moscow, and got TB there. On the outside, she looked like a completely healthy woman. PWID-F-23

Some PLHIV, who are too sick and weak to visit health facilities, need healthcare workers and social workers to come to their homes to provide assistance.

No one comes to our homes. Not once has this happened. Nothing like this has happened. FGD-PLHIV+PWID-M-32

The PLHIV think that their opinions are not considered enough when determining locations for treatment. Some PLHIV feel the need for outpatient treatment care at the Virology Institute

without being referred to the polyclinics in the district where they live, while others would like to receive treatment at the polyclinic or at the AIDS Center.

I was being treated at the Virology Institute. They provide ARVT there, but they transferred me to a polyclinic. Why transfer me when it's convenient here for me to receive [treatment]. I got here with no problems, got tests done and received everything..
FGD-PLHIV+PWID-M-32

The PLHIV mentioned cases when some health facilities lacked medicines for treating concomitant diseases. In such cases, they purchased their own medicines and brought them with them, or they could not purchase the medicines and therefore were not able to receive treatment for their diseases.

We bring medicine ourselves. We buy antibiotics. We just ask them to do the injections.
FGD-PLHIV+PWID-M-32

Some PLHIV think that the state intentionally does not support them and does not provide adequate services so that they would die sooner rather than later. This prejudice against them brings forth anger and a desire to infect everyone – and, especially, doctors – in revenge.

Somebody somewhere thought of a program for those like us in order to simply get rid of us. PWID-PLHIV-M-38

It is clear that PLHIV are receiving an inadequate amount of attention and assistance from non-governmental non-profit organizations. The PLHIV miss the activities of the non-governmental non-profit organization Contact that has been closed and hope that its activities will start again.

They provided support when we were at Contact. There were a variety of classes there. Why did they stop it? FGD-PLHIV+PWID-F-32

Knowledge, attitudes and practices regarding STIs

The PLHIV are well aware of STIs and were able to state names of STIs, symptoms, modes of transmission and methods of protection against STIs (condoms, in particular). The main sources of the PLHIV's knowledge are their own experiences and the experiences of their acquaintances.

Some of the SWs with HIV mentioned other methods of protection aside from condoms. It's possible that these SWs learned of these other methods when they worked abroad or from those who have worked abroad. The SWs with PLHIV consider these methods to be effective.

There is also an injection – they call it rucifin abroad, we call it taracept. You get one injection done, and it's enough for 2 months of protection from everything. FGD-PLHIV+SW-F-38

There are also capsules and creams. Before having contact, you push it there [into the vagina] and it protects you from all disease. You have to let the capsule dissolve for about 20 minutes and then it'll work. FGD-PLHIV+SW-F-34

Condoms are highly accessible. They can be bought at pharmacies and in all stores 24-hours a day or can be received for free from the AIDS Center.

They give them to us at the center. I have a ton of them. They give them to everyone for free. Whoever needs more can take more. FGD-PLHIV+PWID-F-32

Some PLHIV suggest and insist that condoms be used when having sex with “healthy” partners. Others do not necessarily use condoms with casual partners.

I don't agree [to sex without a condom]. Even if someone gives me 1,000 dollars for an orgasm, I won't give it to him without a condom. I don't want to ruin people's lives. FGD-PLHIV+SW-F-38 and PLHIV+SW-F-28-son with HIV

If she's some sort of “whore” [SW], then you don't have to use [a condom]. I mean, if it's casual sex. If it's regular and I know that she's healthy, then you should use it. FGD-PLHIV+PWID-M

The PLHIV think that condom use with a healthy partner depends on the indication of safety concerns over having sex from the partner and not on the concerns of PLHIV themselves.

If a person [a partner] doesn't have any problems with it, then why would I bother? FGD-PLHIV+PWID-F-30

Some of the PLHIV had a positive attitude towards the practice of sexual partners suggesting to each other to use condoms and check their HIV status.

If you tell your boyfriend or girlfriend let's get tested for HIV, there will be more mutual trust. FGD-PLHIV+PWID-F-28

For PWID, buying even condoms with no guarantee of quality is a luxury as they save money for doses instead. PLHIV think that it is nonsense to purchase cheap and unreliable condoms.

Sometimes you don't have enough money. FGD-PLHIV+PWID-F

There are sometimes condoms of poor quality. FGD-PLHIV+PWID-F-32

Some SWs with HIV are concerned that young females who think that they are “clean” do not use condoms and instead give condoms to their children and ask them to give the condoms to their friends.

Particularities in the experiences related to STIs among some PLHIV included neglect towards using condoms, receiving treatment from doctors they know without being registered, or self-

treating, when the PLHIV noted themselves that this does not provide a complete cure but only dulls the symptoms through the use of antibiotics.

I always despised the “rubber” [condoms]. I wasn't interested. I had been with a girl a number of times, and always without the rubber. Once, I contracted trichomaniosis. A neighbor of mine worked at the KVD, she did a smear test for me and treated me at home. FGD-PLHIV+PWID-M

A woman may have gonorrhea for months without knowing that she has it. Men start having pain within three to four days. FGD-PLHIV+PWID-F

We sometimes treat ourselves if we've had it before. We don't want someone to unnecessarily find out about it another time. FGD-PLHIV+PWID-F-32 and FGD-PLHIV+PWID-F

The PLHIV mentioned the introduction of anonymous STI treatment in KVDs, such as “symptomatic” methods, that are free.

Attitudes of PLHIV towards the treatment services at KVDs go back and forth from “OK” to “horrible,” especially in the case of skin diseases. The PLHIV think that skin and venereal diseases should not be treated in the same place. They are afraid to go there to get treated for skin diseases for fear of stigmatization, and for fear of arousing suspicions of acquaintances who think that only people with STIs go to KVDs. For these reasons, people, including PLHIV, prefer self-treatment, treatment by private doctors, or treatment from doctors whom they know do not carry any responsibility for the results and the consequences of treatment.

Out of 100 percent of the people who have these infections [STIs], 80 percent treat themselves. FGD-PLHIV+SW-F-28-son with HIV

After receiving treatment [officially], they'll constantly call you, come, and ask for you through neighbors: have them come, have them come. Anonymity isn't kept. FGD-PLHIV+SW-F-38

Knowledge, attitudes and practices regarding injecting drug use

As in the other groups that discussed issues related to injecting drug use, the PLHIV note a decrease in PWID injecting in groups with one syringe.

The PLHIV noted that people tend to inject drugs in groups in the beginning, when they have not been injecting drugs for long. Then the number of PWID injecting in groups decreases, because the PWID then start to require larger and larger doses and do not want to share with anyone else. Small doses (a part of a “normal” dose) are enough for PWID in the beginning of their addiction

Sometimes alone, sometimes in a group. Usually in a group of 2 people. FGD-PLHIV+PWID-F-26

You start in a group, and then alone. FGD-PLHIV+PWID-F-30

If you have enough money and you don't need to pool in money, it's better to get a fix yourself. FGD-PLHIV+PWID-F-28

I know people, who get a fix themselves. FGD-PLHIV+PWID-F-30

The SWs with HIV noted that using injecting drugs in groups with one syringe has significantly decreased compared to 5-10 years ago. Using one syringe is more common among PLHIV.

Now it's all more serious. If you go to shoot up, each one takes their own syringe. It wasn't like this in the past. You would just wash the syringe and everyone would shoot up. FGD-PLHIV+SW-F-38 and FGD-PLHIV+SW-F-28-son with HIV

People just know more about the risks of HIV now. FGD-PLHIV+SW-F-34

If a person who shoots up with me was infected with HIV, which happened a few times, I used my own [syringe]. FGD-PLHIV+SW-F-28-son with HIV

Some PLHIV said that it is only risky to one syringe, and that using one cup for the injecting water and the injecting water itself does not pose a risk for being infected with HIV or hepatitis C.

The PLHIV said that when PWID inject in groups, they try to protect themselves from contracting HIV by asking questions about the others' HIV status or their experience injecting drugs with PLHIV.

People more often insure themselves now. FGD-PLHIV+PWID-F-30

Before getting a fix, we ask, "Are you with AIDS or not with AIDS? Who else do you shoot up with?" He sometimes lies in order not to have to run and find a new syringe and so that they wouldn't cheat him and not decrease the dose. FGD-PLHIV+PWID-M-32

Like the PWID, the PLHIV said that the availability of heroin has decreased in the market and that the price of heroin has increased. Some PWID are thus starting to switch from heroin to spirits or to "KDTs" – that is, drugs that PWID prepare through drugs containing codeine that are easily available in pharmacies.

Some go to the polyclinics and to the pharmacies or buy "medical alcohol" and use it with water. Hundred grams for 1,000-1,500 som. This is a whole glass of vodka. Others take KDTs. The state made it available. Nowadays there are a lot of those who take it like an injecting drug. FGD-PLHIV+PWID-M and FGD-PLHIV+PWID-F-32

In the past three years, the use of KDTs increase three times. Many [PWID] can already as pharmacists. We are all "pharmacists" here. [Laughing] FGD-PLHIV+PWID-F-28 and FGD-PLHIV+PWID-M

The moment of truth for PLHIV and injecting drug use comes when they understand that it is time to “get off the needle”. They have reached “the end of the rope”, where they do not have any money to buy injecting drugs and have to look for it while suffering from withdrawal symptoms. The PLHIV think, as do the PWID and SWS, that a person who wants to can get rid of the addiction him/herself.

My husband died of an overdose. I was put in jail, and my child was left with the devil knows whom. I don't know how he lived at all. After this, I decided to end it all myself. FGD-F-PLHIV+SW-34

While the PWID displayed negative opinions in regards to substitution therapy, the PLHIV said that they would like for it to return. The PLHIV know about private and public narcology centers where they can receive help, but do not trust them. They consider the private centers to be expensive and useless, while they consider the public narcology center to be a free or inexpensive “humiliation.”

Substitution therapy is necessary for our youth. So that they wouldn't search for where they can buy heroin for cheaper. The cheap [heroin] is weak, but if they happen to end up with a strong [dose] then that it's it – they'll overdose and that's the end. FGD-PLHIV+PWID-F-32

If a person has enough money and is put in a private narcology center, he'll buy drugs while he's there and after he gets out. If a person doesn't have money – that means he needs to go to a public narcology center. FGD-PLHIV+PWID-M

I stayed there for three months. The walls are crushing. It's the same thing over and over again. Groundhog's Day for three months. This isn't treatment. This is humiliation. FGD-PLHIV+PWID-F-30

I went once to the narcology center. The doctor sitting there talking with me is high. He already got a fix [took injecting drugs]. I was a drug addict since I was 15 years old, when I boiled khanka for the first time, and I go and find out that he's “one of us.” And he's going to treat me?! FGD-PLHIV+PWID-M-32

I think the most effective is prison. Nothing will help those who didn't quit there. FGD-PLHIV+SW-F-34

Closing the discussion on treatment services for addiction to injecting drugs, the PLHIV have come to the conclusion that there is no place that can help an individual overcome their addiction, besides in prison where individuals have no choice but to not inject drugs.